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Consultation Response

The UK NSC policy on Congenital Heart Disease screening in newborns

12 December 2013

About us

The Children's Heart Federation is dedicated to helping children with congenital or acquired heart disease and their families in Great Britain and Northern Ireland. We are a parent-led charity consisting of twenty-two member organisations, many of which are registered charities whose main aim is to support families of children with heart conditions.

Comments

The Children's Heart Federation is strongly in favour of the implementation of Pulse Oximetry screening as an additional test to detect Congenital Heart Disease (CHD) in newborns in the UK as soon as possible. Currently screening for congenital heart defects relies on antenatal ultrasonography and postnatal clinical examination; however both tests have a relatively low detection rate and many babies are discharged from hospital before a CHD is diagnosed. A proportion of these may die or present in such a poor clinical condition that the outcome, despite treatment, is compromised. Evidence from the NIHR Health Technology Assessment demonstrates that Pulse Oximetry

testing significantly increases the detection of Congenital Heart Disease in newborns, helping to save lives, prevent physical damage and reduce the resulting distress to families. Screening has been adopted by a number of other countries and is increasingly being implemented by neonatal wards in the UK. The Children's Heart Federation therefore believes that further pilots will cause unnecessary delay to implementation and urges the UK National Screening Committee to recommend that Pulse Oximetry screening is introduced for newborns across all four countries in the UK.

Congenital Heart Disease in Children

Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 babies each year. Between 1 and 2 per 1000 live births (between 700 -1400 babies a year) are life-threatening critical heart defects (CCHD) which, if not diagnosed promptly may lead to collapse and death.

Unfortunately only a third of these conditions are detected during a mother's pregnancy scan and similar number following a clinical examination at birth, meaning that every year babies with potentially lethal but treatable conditions are discharged from hospital without being diagnosed. A proportion of these may die or present in such a poor clinical condition that the outcome, despite treatment, is compromised.

Pulse Oximetry test

Pulse Oximetry is a quick, painless and cheap test measuring oxygen levels in the blood which, when combined with existing screening can increase detection of critical congenital heart defects in babies to over 90%[1] and the Children's Heart Federation is calling on the Government for the universal introduction of the test for all newborns.

[1] Ewer AK. Review of Pulse Oximetry screening for critical congenital heart defects. Current Opinions in Cardiology 2013;28:92-6.

Pulse Oximetry also detects many other important conditions including, other non-critical congenital heart defects, respiratory problems and infections. Some of these respiratory problems and infections are equally lethal if not diagnosed promptly.

Support for Pulse Oximetry test

- Pulse Oximetry is gaining increasing support amongst medical professionals caring for babies with around 1 in 5 hospitals[2] now offering the test. However this sadly leaves a postcode lottery around the country, missing most babies born with a heart condition.

- A NIHR funded Health Technology Assessment involving 6 maternity units in the UK, and 20,055 babies confirmed the accuracy of the Pulse Oximetry test. The UK NSC's own evidence review concluded that "Pulse Oximetry is clinically useful and will increase the number of congenital heart defects in the newborns period".

- Universal screening using Pulse Oximetry has been adopted in many other countries including the United States, Sweden and Switzerland.

- In 2012, leading medical journal, the Lancet[3] published a survey of all UK Lead consultants from all 204 UK neonatal units, showed an overwhelming majority- 76% were considering or had already implemented Pulse Oximetry screening. The same survey showed out of those units who were considering implementation, 36% said the lack of local and national guidelines was a barrier.

- A study into the acceptability of mothers for their newborns to receive the Pulse Oximetry test[4] concluded that mothers were happy for their babies to be tested and that false-positive results did not cause an increase in anxiety.

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[2] Singh A, Ewer AK. Pulse Oximetry screening for critical congenital heart defects: a UK national survey. Lancet 2013;381:535

[3] Singh A, Ewer AK. Pulse Oximetry screening for critical congenital heart defects: a UK national survey. Lancet 2013;381:535

- The Children's Heart Federation has received overwhelming support for the campaign, with over 4,000 parents, carers and other supports calling for Pulse Oximetry testing to be implemented through our Government e-petition[5] and our own petition, which is included in this consultation submission.

Cost

One in five hospitals in the UK have implemented Pulse Oximetry screening for all newborns with no additional funding from Government. The equipment for the test is used regularly in every hospital and costs a few hundred pounds. A modest additional number are needed to be used to screen newborns.

If not detected at birth, Congenital Heart Disease will eventually present itself at hospital, but for some it will be too late. For other children, the cost resulting from physical damage will be very high. Early diagnosis will not only help improve health outcomes for children, it will reduce the costs associated with treating a child whose undiagnosed condition can eventually require them to receive emergency medical attention. For example, a child who collapses from an undiagnosed heart condition may require them to travel in an ambulance, be placed an intensive care and require high dependency care. The outcome of surgery can be worse for babies who are diagnosed late and some may suffer long term neurological impairment as a result of collapse. These consequences can have lifelong cost implications.

False Positives

Nearly all screening programmes will deliver false positive results and Pulse Oximetry is no different. In Birmingham Women's Hospital (BWH) where Pulse Oximetry screening has been implemented for over four years, around 60 newborns babies are picked up a year. Four out of five of the babies who test positive have a significant problem which requires medical intervention. These conditions include

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[4] Ewer AK et al. Pulse Oximetry screening for congenital heart defects in newborn infants: an evaluation of acceptability to mothers. 2012

[5] HM Government e-petition Pulse Oximetry screening for all newborns in the UK http://epetitions.direct.gov.uk/petitions/37286

not only congenital heart defects, but respiratory problems and other infections that may be equally lethal if not diagnosed promptly. Only one out of the five babies who test positive are completely healthy.
To put this into perspective, BWH has over 8000 deliveries a year; 99.2% of the babies tested will pass first time, 60 babies will not pass the test and 48 will have a problem which needs medical attention. Only 12 babies out of 8000 screened will be completely healthy and these babies are usually identified very quickly and no further treatment is necessary.

CHF strongly believe that the early diagnosis of the other important conditions is an additional bonus of the Pulse Oximetry test, allowing early treatment before the baby becomes unwell. We also wish to highlight the acceptability study[6] across six units concluding that false positive results did not cause increased anxiety to mothers.

Availability of echocardiography

Not all hospitals have paediatric echocardiography to perform the follow up test to confirm whether a baby who has tested positively in the Pulse Oximetry test has a congenital heart defect. However, this is also true for babies identified with suspected heart problems following physical examination and this barrier can be overcome with networks developed for the babies to be tested at nearby hospitals. Not all newborns who test positive will need an echocardiogram as they will be diagnosed with another condition. Hospitals have already put systems in place to differentiate when a positive result may indicate a heart condition e.g. observation of physical signs, to minimise the time wasted.

[6] Ewer AK et al. Pulse Oximetry screening for congenital heart defects in newborn infants: an evaluation of acceptability to mothers. 2012

If a specialist is not available at a hospital, advice can easily be obtained to ensure the baby receives the appropriate care. This already happens for the babies who are found to have low oxygen levels by other means (i.e. outside of routine screening) and for babies with abnormal examination.

Staffing time

All babies already have a series of tests at birth including being screened for hearing loss. Pulse Oximetry test takes seconds to do and could easily be introduced alongside these other checks, helping to save children's lives. Hospitals that already screen newborns in this way have achieved this without employing additional staff.

Conclusion

The Children's Heart Federation strongly urges the UK National Screening Committee to recommend the implementation of Pulse Oximetry screening for all newborns in the UK. The test significantly increases the detection of heart defects in newborns. Detection of congenital heart defects at birth will give children the best possible chance for life-saving treatment; prevent physical damage caused to the child and reduce the resulting distress to their families. As the test also detects respiratory problems and other infections that may be equally lethal if not diagnosed promptly, CHF believe that this is an additional bonus of the test. The UK NSC must recognise that one in five hospitals who screen newborns using Pulse Oximetry support this view and have not reported problems picking up these additional conditions. The successful implementation of Pulse Oximetry by these hospitals, with no additional Government funding, provides overwhelming evidence for the implementation across the UK.

We urge the UK NSC to address the issue of low detection of congenital heart defects from current screening policy and recommend the implementation of Pulse Oximetry to ensure that all newborns across the UK have access to this potentially lifesaving test.

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Clinicians Views

12 December 2013

In Their Own Words

One in five hospitals in the UK offer Pulse Oximetry screening to newborns. We contacted Consultant Neonatologists and Paediatricians at these hospitals and asked them to address criticisms surrounding the testing relating to false positives and additional burdens on neonatal units. We asked for information on any problems experienced through implementing the test. Their opinions were submitted as part of a group, open discussion, and below are their responses in their own words. Some have also sent their experiences to the UK National Screening Committee directly.

Consultant Paediatrician

“We introduced post-ductal screening 3 months ago and have had no positive results so far! The screening has been easily integrated into practice and feedback is that midwives particularly feel more confident in using Pulse Oximetry generally than they were before. Greater Manchester Neonatal Network has agreed that all units should be offering differential SaO2 by end of 2014.”

Consultant Neonatologist

“I agree with the points raised [by others].

The whole idea that we are overwhelmed with “false positives” (or unascertained hypoxic babies who have not yet developed clinical symptoms) is such rubbish - simply untrue. I only hope that they [the NSC] will at the very least proceed with a pilot.

I very much hope that everyone who can has submitted just a few lines on their experience – I cannot believe any [Neonatologist who uses Pulse Oximetry] could have regretted screening any baby. We have not been collecting data, but there are far and away more babies who turn out to be ill than there are ones who are asymptomatic, admitted and turn out not to have any kind of problem (they are rare as rocking horse manure in my impression).”

Consultant Pediatrician

“I agree with all that everyone has said.

“…we have done this screening since 2008. We have 6000 deliveries a year. Using Pulse Oximetry has allowed early diagnosis of several congenital cardiac abnormalities, PPHN and other severe morbidities.

I can recall one case where improving with a few hours observation on SCBU. I do not know of any false positive referrals to the regional cardiology service. Other hospitals were worried about flooding the regional service. This simply has not happened. We have no doubt that whilst imperfect, like all tests, it is better done than not done."

Consultant Neonatologist | Neonatal Clinical Lead

"To be honest, it depends what you mean by a 'false positive'. I am not sure we have had any babies with abnormal Pulse Oximetry measurements who were completely asymptomatic, so they may not have Congenital heart disease, but they often have something else that needs checking out (early sepsis/ respiratory problems etc).

If your outcome is purely to use Pulse Oximetry for Congenital Heart defect screening I would be more concerned about the 'false *negatives*'. We have had instances where babies have had 'normal' saturations during the Examination of the Newborn and then turned up with Cardiac failure due to significant Mitral Valve problems.

It is only a screening tool as part of EoN - not diagnostic and should be seen in that context to alert people to check the baby further. As with the EoN as a whole, explanations should be given to parents about the purpose and limitations of this as a screening tool.

We are certainly not' over-burdened' on our NICU by this tool and have found it very useful for the midwives and doctors to be familiar with its use as part our assessment of babies - well or otherwise."

Consultant Paediatrician

“I agree with all the comments, [...]and have fed back to the NSC.”

Consultant Paediatrician & Clinical Lead

Our experience of implementing and using Pulse Oximetry has been very positive and trouble free”.

Consultant Neonatologist

“We have been doing universal pulse-ox check since September 2012 which has been going well and we managed to pick up some babies with respiratory problems and few babies with cardiac conditions early while they were asymptomatic. Our midwives who do the test do not feel overburdened to do this simple test and they do as part checking weight when they reach postnatal wards. As long as one of the sats (pre or post) above 94 and clinicial exam is normal, we do repeat 2 times (1 hour apart) before calling as positive test or admitting to NNU . I can remember only 1 asymptomatic baby who was genuinely false-positive (although borderline sats) on 3 testings who needed heart scan which then ruled our any significantly abnormalities. So from our experience, we did not have any increased heart scan burden since implementing the test.
We have drafted a regional guideline (including flow chart) which will be implemented by January 2013 in most of the neonatal units in West Midlands (2 newborn networks).

Parents' Views

12 December 2013

We contacted parents whose child's heart conditions had not been diagnosed before birth and asked them to share their experiences. In many of these examples, the child's heart condition was not diagnosed at birth and required emergency treatment as a result. The following stories are told in the parents' own words.

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]

Address: [redacted]

Information about child

Name: [redacted]

Age: **4**

How old when detected: **9 days**

Heart condition: **Hypoplastice Left Heart Syndrome**

Treatment received: **Norwood Procedure, Stages 1 and 2**

Tested for heart conditions at birth? Yes/No **No**

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

When [redacted] was born, all seemed perfectly fine, and he was a normal, healthy baby. But a few hours into his life, he started to be sick, and he was throwing up blood. He was taken away from me right away and moved into the neonatal unit and was treated for a lung infection. It was very touch and go but after a week he seemed to start to get a lot better. Which is when we got him home and when the real problems started!

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

As above, when [redacted] was born he got very poorly just a few hours into his life and started being sick, but it was blood. He was taken down to the neonatal unit. They were unsure what was wrong with him. [redacted] was put into an incubator and needed help breathing etc. In the end [redacted] was treated for a lung infection. For the first few days he was extremely poorly, but he started to get over it. When [redacted] was a week old, we got to take him home (which was a Thursday). I started to grow concerned for [redacted] on the Friday. He never cried. He slept all the time, and wasn't feeding at all. His hands and feet were so, so cold. I remember I tried everything I could to get him warm. But he just stayed cold.

On the Saturday morning, I called the doctor at the neonatal unit. I explained all of these things, but he just told me not to worry, and that he would be ok and its normal for him to be like this. I didn't believe him. And thank god I didn't listen to him! Me and my husband jumped straight into the car and right to A&E. [redacted] was seen right away by triage, and was rushed right through. We did not have a clue what was happening. He was struggling to breath, he just wasn't with it. Within in an hour our baby was surrounded by nurses and doctors. He had so many lines going in his body to keep him alive. He was rushed straight back to the neonatal unit. Me and my husband were put into a room. And we waited. For hours. For so long.

Eventually we were called through to see him. It was awful. We were told he would have to be taken to another hospital where he would have to be seen by somebody else. At this point we still did not have a clue what was going on. He was eventually taken to the children's hospital by ambulance. We all arrived at about 2am. Time seemed to go so slowly. He was seen by a cardiologist, and she sat down and explained what could happen. He would either have to have the more complicated surgery, or just minor surgery to open the valves more. A few days later he was taken in an Ambulance to another hospital where we found he would have to have the more complicated surgery. So at just 13 days old he was operated on. After surgery, he started to lose a lot of blood and went into cardiac arrest. But luckily, the surgeons were able to save him.

Has your child received treatment or surgery?

[redacted] has had 2 major open heart surgeries and still has 1 to go within the next year or so. He has also had a minor operation, his cardiac catheter. He goes to hospital every 6 months for a check up with his cardiologist.

How is your child now doing now? How are you feeling and coping?

[redacted] is doing extremely well. We were told when we originally found out, that his 3rd operation would be when he was between the ages of 3 to 4. [redacted] is 4 and a half now and still doing so well. He has just recently had his cardiologist appt. But he is doing so well that they still haven't put him forward for his next operation. [redacted] is amazing, and we just get on with our everyday lives. He does get tired a lot more easily and can't keep us with the other children at school for example in sports days etc. In all honesty, you just kind of forget about it, until you have a hospital appointment or something. Then it all comes flooding back. Like now, filling out this form, I am in tears as it is just fetching it all back. We are coping well just now. But things are about to get harder, as we know [redacted] is due for his 3rd operation.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

I think this campaign is amazing. I cannot express how important it is for this to go ahead. I nearly lost my baby. So many times. And this could have been prevented just by one simple test when he was born.

Received: Thu 05/09/2013 15:36

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 15
How old when detected: 12 days
Heart condition: Co-arctation
Treatment received: Repair of the Co-arctation
Tested for heart conditions at birth? Yes/No No

Additional information

Did you notice that your baby was unwell before her heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

When [redacted] was born we raised some concerns that [redacted] was having breathing difficulties. They allayed our fears by checking her and said that she was ok. This happened on numerous occasions.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

[redacted] went home from hospital without any concerns from the doctors. A day or two passed and we again became concerned about her breathing and not taking her milk and erratic breathing. We took her to the local surgery where the GP examined [redacted]. (We were shocked by his response ;) He checked her heart and breathing and asked us “how long has she been like this?” We responded by saying “from day one.” He went away without any explanation as to what he was thinking but asked us “could we drive and do we have transport?” He came back after about a 5 minute wait snatched [redacted] out of [redacted]’s arms and starting doing mouth to mouth whilst another doctor did heart massage. The Dr said “I’ve called for an ambulance and tried getting a police escort but there was no answer from them.” He wrapped her in foil to keep her warm. (We were gob smacked) We didn’t have a clue what was happening. We were quickly rushed to the NICU where [redacted] was stabilised. This was a scary time and we were still in limbo as to what was happening.

We were advised that [redacted] was really unwell and will need to go to another hospital. She was transferred using a special ambulance and we were told not to follow the ambulance but to make our own way as we could hinder her treatment. We got to Cardiff bewildered as to what had happened. We found out where [redacted] was being treated and wired up and had to wait for what seemed a life time before having any information as to what was going on.

The paediatric consultant came and spoke to us giving us all the likely scenarios and outcomes we were to expect or could happen. We were told that she’ll need an

operation to correct a heart condition but was too unwell to do it there and then. The operation took place when [redacted] was 13 days old.
The oddity about the whole thing is that [redacted] was placed on a normal ward not long after the operation as if nothing had happened and we were made to get on with it.

Has your child received treatment or surgery?

[redacted] had an operation when she was about 14/15days old. This was to repair the Co-arctation.

How is your child now doing now? How are you feeling and coping?

[redacted] is doing well and is 15 years of age. She leads a fairly active and normal life and wants to sing professionally. She has had numerous check-ups on an annual basis some of which have been quite worrying. In one of the check-ups it was discovered that [redacted] has Sub – aortic Stenosis. She is Bi-cuspid and there was mention of a tiny leak in one of her valves. The Specialist has suggested that she is seen in approx. 2 years' time showing that he's not really concerned by the current problems that she has.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

It is important that all children get tested, allowing all children to have a better start in life

Received: Fri 13/09/2013 01:29

Pulse Oximetry Campaign – telling your story

Thanks again for your help!

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 9 months
How old when detected: 11 days
Heart condition: Transposition of the Great Arteries
Treatment received: Balloon Septostomy followed by Arterial Switch Operation
Tested for heart conditions at birth? Yes/No No

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

I found him very fussy when breastfeeding, I raised it with visiting midwives and health visitors and they suggested I burp him more.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

We had our final postnatal midwife appointment; it was actually our discharge appointment where they were planning to sign us off their books. The appointment

went as normal to begin with, then the midwife started to take long looks at [redacted], she brought him over to the window and held him up to the light. She then told me she thought he looked a little 'dusky' in appearance. I was unsure what this meant; she mentioned something about oxygen but was not specific. She said it was probably nothing but wanted us to go to the local children's hospital to get checked out.
At the hospital, they took one look at [redacted] and rushed him straight through to what I now know to be the resuscitation room. Within minutes, he was covered in wires, oxygen mask and drips. It happened so fast, we were stunned, my 3 year old was also with us - so we tried to keep calm for his benefit. After some hours, the consultant sat us down and explained to his that he had a serious heart condition and would require open heart surgery. We were horrified, some part of me still felt that it was all a mistake and we would probably get out the next day. I phoned my parents who jumped on the next plane from Ireland and were there that evening to look after my 3 year old while I stayed in hospital with [redacted].

Has your child received treatment or surgery?
Keyhole surgery was carried out the evening we arrived in hospital called a 'balloon septostomy', the doctors described this as 'buying him more time' until his open heart surgery which was carried out 5 days later when he was 16 days old.

How is your child now doing now? How are you feeling and coping?
He has recovered very well - he has gained weight and is an extremely happy, smiley baby. I am obviously anxious although I try hard to keep this in check, we were advised to treat him as a normal baby from here on in but I'm not sure if I will ever be able to do that. I worry constantly about the implications of his surgery on his future. I also 'relive' a lot of our experience- it all happened so quickly, I think I have had little time to fully process it and am still doing that.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
I would love to see Pulse Ox rolled out in the newborn screening, especially as its so straightforward and effective. The campaign needs as much publicity as possible.

Received: Thu 05/09/2013 15:22

Pulse Oximetry Campaign – telling your story

Information about you
Name: [redacted]
Address[redacted]
Information about child
Name: [redacted]
Age: 18 months
How old when detected: 6 weeks old
Heart condition: Coactation of the Aorta, 2 VSD's and PDA
Treatment received: Yes

Tested for heart conditions at birth? Yes/No NO.

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

Yes, I noticed that his breathing wasn't the same as my other two children; he sucked his tummy under his ribs when breathing in. He didn't feed very well which was put down to colic. I raised concerns with his health visitor at around 3 weeks old to be told that all was ok. We noticed that his weight gain was slow and that his legs were very thin compared to our other two children as babies.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

[redacted] was admitted to hospital after he went grey and floppy during a family outing. He was taken by ambulance to casualty where they thought he had a chest infection. After an x-ray it was revealed that his heart was enlarged and his lungs were saturated with fluid. During feeds the doctors noticed that his SATS kept dropping so he was given an NG tube. A cardiology appointment was arranged and from then we were told that he was in severe heart failure and was dying.

I remember feeling sick and completely numb, I kept repeating over and over that he was going to die and was taken to a side room by my mother in law who was the ward sister on the children's ward at the time. Everyone was in shock, no one could ever have anticipated just how poorly he was. Telling family was horrific, I had to have my mother in law tell my father as I broke down in tears.

Has your child received treatment or surgery?

Yes, [redacted] received heart surgery to correct the coactation and PDA but they left the holes alone. He was on diuretics for a year after surgery and high calorie milk due to his lack of weight gain.

How is your child now doing now? How are you feeling and coping?

He is doing absolutely fantastic, he's a happy, thriving little boy who has come on leaps and bounds. I don't think I coped very well at first as it was all so new to us but it got easier. I still wonder why it wasn't detected as I had so many scans during my pregnancy due to me having impaired blood sugars. I kept being told he would be a huge baby and was given a c section 2 weeks early for him to come out 6lbs 13 which is where alarm bells started ringing for me. For a while I was very angry for it not being found but over time I realised that the outcome would have been the same regardless of when we found out.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

I think it's absolutely fantastic! This could save many babies lives, we were one of the lucky families who found out late but our child was ok. This testing could prevent many unnecessary deaths and give families time to prepare and arrange childcare for other children if needs be and be prepared for surgery. We had this all sprung on us within 48 hours and it was quite traumatic, not only for us but for our other children who had to be sent 200 miles away to stay with family while we looked after the baby at home. So not only did we have the stress of having a very sick child, we were also concerned about our other boys.

Received: Thu 05/09/2013 14:43

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 5
How old when detected: 5.5 months old
Heart condition: Large VSD and 2 ASDs
Treatment received: Heart surgery at 6 months old
Tested for heart conditions at birth? Yes/**No**

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

[redacted] was slightly under weight at her 6 weeks check up so the doctor told me to have her weighed every 2 weeks at the clinic with the Health Visitors. From about 7 weeks onwards she was struggling to feed, always tired, unhappy, bringing up most of her milk, a persistent cough and always sweating. She was gaining weight very slowly; I had to stop breast feeding around 7 weeks because she was too tired to feed off me.

I did go to the doctors a few times because of her coughing and they gave me some nasal spray & told me it was a cold. I did mention to the GP about her heart beating fast all the time, but he listened to it and said it "was just the way she was"!

I also mentioned different symptoms to the health visitors, yet none of them mentioned they could be related to a heart problem. It was only when she was 5.5 months old and was barely gaining weight, they told me to go and see the GP. The following day I went and a new GP listened to her heart and thought she could hear a murmur. She then referred me to hospital.

At this point she weighed just under 11lbs so she was still wearing her newborn clothes!

When I went home after they mentioned her having a murmur I looked it up and [redacted] had every symptom listed under CHD!

I then had a letter saying they would see me 2 months later, but by the end of the week I went back to the GP because [redacted] had lost weight and the GP rang another hospital and they agreed to see her straightaway.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

When I went to hospital I was panicking, I was worried they were going to tell me she would need a heart transplant or worse! When we got to hospital they scanned her heart and I could hear them saying she was in complete heart failure, they took me into a room and told me then that she would need surgery. I was very upset and was in complete shock, you just think the worse that they are going to die, especially when they tell you they need to operate.

I could not believe all this time she had been struggling to feed and nobody picked up on her symptoms. All that time she could have been on medication and she would have had the operation around 3 months old I believe. I was very stressed and

worried, I had to stay there with her and my husband had to be at home with our 20 month old son.
The following day I had to go to another hospital and they put her on diuretics and captopril which immediately helped take the fluid off her lunges and she was able to actually keep some milk down! She was put on infatrini to help her gain weight as soon as possible ready for the operation. One week later she had the operation and she was in Intensive Care for around 4/5 days because her heart had been working so hard for all that time it took her a little longer to recover, we then went back on the ward for about 3 more weeks.
The nurses at hospital were shocked that I had only just found out the week before about [redacted]'s heart problem, they said I had done well to keep her going, as I was feeding her little and often.
Her operation took around 5 hours, it took a little longer because her heart was so enlarged when the surgeon opened up her chest they had to go in a slightly different way to fix it. It was longest day of my life! When you see them in intensive care plugged into all the machines I just felt sick, every time the alarms go off you think they are going to die. The first couple of days were awful, she had a funny heart rhythm after the operation that took a while to settle, and then she had an infection, the whole time you just feel like you going to lose them. I did not sleep very much at all when I was there.

Has your child received treatment or surgery?
Yes she is 5 now, she had surgery at 6 months old.

How is your child now doing now? How are you feeling and coping?
She has regular checkups, it was yearly, then 2 years and her next one is in 2 years time. I still feel very sad when I think about it and that she could have actually died if they had left it much longer before diagnosis. The first couple of years after the operation I could barely speak about it without getting upset.
The fact she could have been on medication from birth and given special milk to help prepare her for surgery and it would have saved all those months of struggling as a newborn to feed, and also I was constantly trying to feed her little and often to get her to gain weight. If we had known from birth we would have been much more prepared & would have felt happier knowing she was getting the right care from the start.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
Brilliant idea! They give us information on meningitis, cot death and other illnesses, why do they not give more information on CHDs? I asked my doctors why there is no leaflet outlining symptoms and they said they do not want to panic parents! I would rather have been given the information sooner because maybe I might have noticed [redacted]'s symptoms quicker! **Knowledge is power as they say!**
I think it should be a mandatory test in all hospitals, it only takes a few minutes, and it could save so many babies lives. I have read about so many parents who babies have died because it was too late because they were not diagnosed in time. It is one of the highest birth defects so why don't we test for it already?
It is such a simple test that could save lives!
Received Sat 07/09/2013 00:49

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 8
How old when detected: 24 hours
Heart condition: Pulmonary atresia, with ventricular septal defect
Treatment received: Shunt at 5 days old. Open heart surgery at 5 months old to repair the septal defect, and insert a tube between his heart and his lungs, with a working valve.
Tested for heart conditions at birth? No

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

[redacted] was born in the early hours of a Sunday morning. It had been a difficult pregnancy, and he was very small, only 5 lbs. My other two sons were 9lb 3oz, and 9lb 12oz, and so we were concerned at his size, but were told this was 'just one of those things'.

24 hours after he was born I was unwell, and he was being looked after by the midwives out at their desk in the maternity ward. We all have a tube that bypasses the lungs, as we do not use our lungs of course before being born. That by pass closes about 24 hours after we are born, as we use our lungs to oxygenise our blood directly from our heart. [redacted] was born with no tube connecting his heart and lungs.

That meant for [redacted] the tube was gradually and fatally closing. Luckily, as he was with the midwives, they realised that he was struggling for breath. They rushed him down to the ICU. It is most probable that they saved his life. Had he been with next to me in a cot, and I had been asleep, he would almost certainly have just slipped away. Similarly, had I not had a caesarean section, I may well have been sent home with him, as he was my third baby, and he would have died.

[redacted] was not tested for any heart problems and we were told he would have been tested at some point over the 'next few days. He was also born on a Sunday, I do not know whether that contributed, which is course a situation of course much in the news nowadays.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

[redacted] is now a beautiful and very special 8 year old, albeit still with a serious heart condition. His heart condition would have been spotted by any simple test, or even just a trained doctor listening to his heart. His saturation levels were dropping all his first day of life. To contemplate that he so nearly died due to the simplest of tests not being carried out is nearly unimaginable.

When I was pregnant, we had a scan at 5 months. I vividly recall the sonographer taking a long time to look at his heart, and then telling us 'there's something I can't quite see, but I'm sure it is fine'. It is obvious now that what she could not see was a

complete pulmonary tube between his heart and his lungs. That, to my mind, adds greatly to the campaign to have all new borns tested, as these conditions are not always picked up on scans, even very major ones.

[redacted]'s first few days of life were a devastating roller coaster, which was all totally avoidable. My memory was of being woken up in the middle of the night to be told he was very ill, he had stopped breathing, and I needed to call my husband to the hospital straight away. I still relive that moment. We had had a wonderful day the day before celebrating him being born, and showing him to our other sons. To then have to tell them that [redacted] was so ill was devastating for the whole family. Had we been told shortly after he was born that there was a problem, but that an operation could fix it, albeit still a serious problem, the whole family would have coped so much better.

We had not named him at that time, as we thought we had all the time in the world with our son, and could get to know him before we chose a name. When we were taken to see him in a tiny incubator down in the ICU, they told us that we may think we ought to give him a name. It dawned on us that this was because at that point they were not sure he would survive due to the tube closing.
Testing at birth would have stopped all that.

Has your child received treatment or surgery?
[redacted] had a shunt operation at 5 months old, and open heart surgery at 5 months. He is waiting his next open heart surgery which will again replace the tube and valve.

How is your child now doing now? How are you feeling and coping?
[redacted] lives a very near normal life, due to our efforts to treat him as a normal child. He gets very tired, and knows he has a poorly heart. We do not know what the future will hold, but if the operations go well, he will live a full life.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
I am sure you have read many other stories like mine. As I say above, such a simple test can save lives. Surely it should happen.

Received: Sun 08/09/2013 11:21

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 18 months
How old when detected: 1 -2 hours old
Heart condition: Right atrial Isomerism, Total anomalous pulmonary venous drainage, Atrioventricular septal defect, double outlet right ventricle Pulmonary Stenosis
Treatment received: No surgery as of yet will have TAPVD repair and bi-directional Glenn when needed
Tested for heart conditions at birth? Yes

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

At 1-2 hours old the midwife who delivered [redacted] noticed she was looking quite blue and was breathing very hard. I too noticed her chest dipping in while breathing and kept asking if all was ok.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

After the midwife noticed [redacted]'s colour and breathing she done pulse ox test and [redacted] sats was 69 % from there she went straight up to SCBU. They did a heart scan and noticed problems so arranged for her to be transferred to another hospital, to be seen by cardiologists that night.
Once we were told her diagnosis our world came crashing down we were truly devastated and I was sure I was going to lose my beautiful newborn, I felt guilt for my other son who was only 23 months at the time for deciding to have another baby and putting us all through so much. even now 18 months in I still struggle to come to terms with [redacted]'s diagnosis, We're very lucky to have amazing support all around us. We just take our whole life one day at a time now.

Has your child received treatment or surgery?

[redacted] spent 5 weeks in hospital after birth having ct scans, a bronchoscopy, many x-rays, ECG's and Echos, Then had a diagnostic heart cath June 2012,

How is your child now doing now? How are you feeling and coping?

[redacted] is doing well considering she hasn't yet had the surgery doctors told us she would need to survive within a few months of life, she is very different from most 18 month olds in many ways, I just make the most of everyday with my lovely family, I do have nights where I replay all the negative conversations we had with doctors, and worry whether I will see my girl grow up, it breaks my heart even writing that.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
I think it's a great campaign and would love to help in my area in some way, the pulse ox saved my babies life, and it could save many more babies if all newborns had the pulse ox carried out.

Received: Thu 05/09/2013 21:17

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

About my son his name is [redacted]
Age 10
He was 3 and a half weeks when he was diagnosed with Transposition of the great arteries (TGA)
Treatment received: Balloon atrial septostomy then Surgical repair - the 'switch procedure
Tested for heart conditions at birth? No

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?
[redacted] was born a very healthy baby at 8lb 2oz. I think from day one I knew something was wrong, but as a1st time mum I was unsure.
We took [redacted] home at 1st he was eating and sleeping like any baby. As the weeks went on something was telling me his not right. He was feeding less and was a funny colour and sleeping all the time.
I took him to my GP who sent us to A & E. Within an hour I was being told he had some wrong with his heart but they could not tell me what. He needed to get to the hospital ASAP. I'll never forget they told me to say goodbye as I could not go with him in the ambulance and he may not make it to the hospital as he was so ill.
His oxygen levels had gone down to 52%.
The next 3 weeks went so fast like a bad dream. We took a cab to guys the longest drive of my life. When we got there they gave [redacted] a Balloon atrial septostomy to allow increased mixing of the blood. The next morning he had the Surgical repair - the 'switch procedure'. He was in ICU for a few days
Then he went up on to a ward. When he woke up it was unreal like a new baby his eyes open wide and he was a lovely pink colour like he had never been before. The doctors told me if I had not taken [redacted] to hospital when I did he would have died within 48hours he was that ill. He was lucky to have lasted 3 weeks at home with his condition.

Has your child received treatment or surgery?
[redacted] later had a second operation one year ago due to compression on his left air way from one of his arteries.
How is your child now doing now? How are you feeling and coping?
Lucky for us [redacted] 's story has a happy ending. He is a happy 10 year old running round playing football. When I think how close I came to him not making it I get so upset even writing this had been hard bringing it all back. That sick feeling knowing my baby was so sick and there was not a thing I could do just sit and watch.
What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
I would not want anyone to feel like that that why Pulse Oximetry testing is a must one small test to save someone so much heart ache. [redacted] had had the test he could of been born in the guys and had the operation at birth.

Received: Thu 05/09/2013 22:14

Pulse Oximetry Campaign – telling your story

Information about you
Name: [redacted]
Address: [redacted]

Information about child
Name: [redacted]
Age: 1 year
How old when detected: 6 weeks
Heart condition: Pulmonary Stenosis (critical), Ventricular Hypertrophy, Ventricular Septal Defect
Treatment received: Balloon Valvotomy
Tested for heart conditions at birth? Yes/No : No

Additional information
Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?
[redacted] showed absolutely no symptoms before her diagnosis. As far as we knew she was a healthy, happy, smiley little girl. All of the health professionals she came into contact with commented on how she was a lovely colour and thriving. We had no idea she was poorly, it came as a complete shock to us when we found out about her heart conditions.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?
[redacted] was always a happy baby who fed well and slept well. When she was 5 weeks and 6 days old she wasn't her usual self; she refused the breast, wouldn't sleep and screamed uncontrollably for the entire day. She couldn't be settled or comforted. I was so worried that I called the children's ward at our local hospital for

advice. They told me she was probably suffering from Colic but if I was still concerned I could bring her to A&E. She continually got worse so my husband and I took her in.
During her preliminary check in A&E her Oxygen saturation was checked and found to be in the low 70%. When the Doctor checked her over he asked us if we knew she had a heart murmur. It was news to us; we'd been told she was perfect at her post-natal check. They called in a Paediatric Consultant (after 6pm on a Sunday night) who, after listening to her heart, requested X-Rays, an Electrocardiogram, blood tests and for her to be started on antibiotics and Oxygen. As soon as the X-Rays were back the consultant forwarded them to another hospital. [redacted] was admitted to the Children's Ward while we waited. She received antibiotics via a cannula in her hand and was started on Humidified Oxygen. Later that evening we were informed she was to be transferred to the other hospital by ambulance in the morning. We weren't told what was wrong with our baby.
At the other hospital [redacted] received an Echocardiogram. The consultant came in to explain the results to us. He told us she had Pulmonary Stenosis and that she was in critical condition. I broke down and my husband tried to remain strong, wrapping his arms around me. I looked at my beautiful baby cradled in my arms and was terrified for her. The consultant explained the condition to us and said she needed a procedure immediately; he was very surprised she had lived to six weeks. Her pulmonary valve was thickened so much that the blood couldn't get through. This meant that her heart had to work harder to get the blood to her lungs. As a result, the muscle in her ventricle was extremely enlarged, dangerously increasing the pressure in her little heart to six times the normal level (the pressure in a normal heart is between 15 and 20. [redacted]'s was 120). This is known as Ventricular Hypertrophy. They also found a Ventricular Septal Defect. The wall separating her left and right ventricles had a hole in it. This actually saved her life! The hole acted as a release valve for the pressure in her heart. It allowed the deoxygenated (blue) blood to pass through the hole and mix with the oxygenated (red) blood and travel around her body. If it wasn't for this hole she'd have had a fatal heart attack.
We were devastated. Couldn't believe what we were hearing. Our world was crumbling around us. Our thriving, happy little baby had been so close to the unthinkable and we had been completely oblivious! We were asked if we needed some time to make a decision about the procedure. We didn't. As far as we were concerned there was no question about it, she was having the surgery. My husband signed the consent form giving them permission to perform a Balloon Valvotomy. We were given some time to process the information before being admitted to the ward.
In the nursery on Ward 23 the Cardiologist who was to perform the procedure came to tell us the risks etc. He told us there was a 12% chance that our baby wouldn't make it through the anaesthetic but at that point they had no option but to operate. We were absolutely terrified. It was so hard trying to stay strong for our fragile little daughter.
We contacted our parents to tell them what was going on. I cried through the entire conversation. My mam told me she was going to pray for [redacted] that night, and not to worry because she was in the best hands. I didn't want to hear her telling me that everything would be ok. She didn't know. She wasn't qualified to tell us that. I knew she was trying to comfort me but it wasn't working. I was sinking; I just wanted my

little girl to be ok. My husband was my rock. He stayed strong for [redacted] because I couldn't.

Has your child received treatment or surgery?
The next morning we were allowed to go to theatre with [redacted] while she was anaesthetised. They even kept her favourite toy by her side. Our precious little girl smiled right up until they administered the anaesthetic into her tiny hand. It was heart wrenching. She had a procedure called a Balloon Valvotomy. A balloon catheter was inserted into her heart via the artery in her groin and the balloon was inflated when it reached her pulmonary valve to break it. The Cardiologist told us the procedure had been a success. It was a huge weight lifted. He explained that they had used a second larger balloon because the first hadn't worked. We were allowed to watch the video of her procedure so we could see exactly what had happened. It was amazing to see.
When she was due to come round from the anaesthetic we were taken to her. She looked so tiny in her little hospital gown. The cannula in her hand had stopped working. They couldn't get into a vein in her foot so they put two cannulas in her head. She was covered in tubes. It would have been terrifying if it hadn't been such a relief just to see her. They had saved her life.

How is your child now doing now? How are you feeling and coping?
At first it was very difficult. My husband and I would take it in turns to sleep so the other could watch her to make sure she was breathing while she slept. We did a lot of research into her heart conditions so that we can prepare ourselves for the different possibilities the future may hold, so that we know of any restrictions and complications that may occur. [redacted] is thriving now. Her last Echocardiogram showed that the muscle in her ventricle has shrunk, reducing the pressure inside her heart significantly. If the muscle hadn't shrunk she would have needed open heart surgery to cut away some of the muscle mass. Her Pulmonary valve is tightening slightly and leaking blood a little but her Cardiologist is happy with her progress.
If she continues to progress the way she is at the moment, she may never need further surgery. We are so thankful that we found out about her condition before it was too late, and that the amazing people at the hospital were able to save her life. There are no words to describe how lucky we feel. Our biggest wish is for our precious little angel to be healthy.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
The CHF's campaign is a brilliant idea. It is just a shame there has to be a campaign at all. It is such an important test and so simple to conduct. If the Pulse Oximetry testing was mandatory and carried out automatically at birth, so many tiny lives would be saved.

Received: Sat 07/09/2013 23:03

Pulse Oximetry Campaign – telling your story

Information about you

Name: [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 2 Years 6 months
How old when detected: 10 weeks old
Heart condition: VSD and Leaky aortic valve
Treatment received: Was treated at 10 weeks old by medication as was in heart failure, had ohs twice in Feb 2011, has 6 month checkups.
Tested for heart conditions at birth? /No
Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

When [redacted] was born he spent most of his time asleep, he would not take to breastfeeding so we was syringe feeding him, he would also struggle with the bottle and taking an hr to get feeds into him. [redacted] was sick a lot, his heartbeat was also fast. I took him to the doctors lots of times and was told he had colic and was a lazy baby. He was not putting on weight each week and even the hv said boys are lazy. Each Doctors appointment they did not once listen to his heart

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

We found out [redacted] had a heart condition when we took him for his 10 week check up, I took my mum with me as felt the Doctors just thought I was an over protective 1st time mum. The Doctor listened to [redacted]'s heart and said he has a large heart Murmur. Within a week we received a hospital appointment to be seen at our local hospital. They listened to his heart and did ECG and eco on him. This is where we found he had a VSD. I was in shock when they said about his VSD and found it very scary as the doctors was racing around getting him started on diuretics, I did also feel relieved as they found out the reason for poor weight gain and being very tired and he could be treated for his heart failure. My family was very upset but very supportive with [redacted]. I did struggle a lot with [redacted] as it was taking an hr to feed him and I found it very stressful and I did get upset a lot.

Has your child received treatment or surgery?

[redacted] had OHS in Feb 2011 aged 1 at hospital where they closed his hole in his heart, and try to mend the valve, while he was there after his OHS he did not seem to get better and a week later we found out that [redacted]'s patch on his heart had come away so would need to be closed again, 2 weeks after his 1st op he went back and had another open heart op to re-close the hole. He spent 3 weeks in hospital. On his post op check up he had his diuretics reduced and then stopped them. [redacted] now has 6 month check-ups done.

How is your child now doing now? How are you feeling and coping?
[redacted] is doing well after his open heart, he is a cheeky 2 year and a half year old, he has now put on weight and is nearly up to the line on the chart for his weight he was born on. [redacted] still has a leaky aortic valve and has been told this will require another open heart op before he is fully grown to repair or replace the valve. I am coping well with [redacted] and now catching up on time that I feel I missed out on when we was younger as I was always struggling to feed him and found it very stressful.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
I think CHF campaign is brilliant idea, I have been involved with getting signatures for the petition and I am hoping that England follows in the steps on other countries who has now made this test the law for all new born babies to be tested. If [redacted] had been tested perhaps it would not have taken until 10 weeks old to find out he was in heart failure and would also save some babies from dying.

Received: Fri 06/09/2013 10:51

Pulse Oximetry Campaign – telling your story

Information about you
Name: [redacted]
Address: [redacted]

Information about child
Name: [redacted]
Age: 12
How old when detected: 3
Heart condition: Vascular ring with a left abbarrant subclavian artery
Treatment received: corrective surgery
Tested for heart conditions at birth? No

Additional information
Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?
At 8 weeks old [redacted] developed very noisy breathing. We took her for her first lot of immunisations at the doctors and the doctor said she was too ill for her jabs and that she had asthma. She was put on inhalers and sent home. That weekend we had a bad night with her and realised there was more to it so took her to our local A&E department the following day. Here she was admitted with bad bronchitis. When we told her the doctor had diagnosed her with asthma they were shocked as they said no child under 2 should be diagnosed with that unless they had had reoccurring attacks. She was put into a oxygen box as her levels were very low and was tube fed. It was horrible not being able to cuddle her.
Thinking back, whenever they tried to insert a tube down into her throat they had trouble getting it down. After diagnosis (nearly 3 years later) we realised why. She

was in hospital for over two weeks and had various tests but no tests were related to her heart. She was tested for cystic fibrosis which was heartbreaking to watch. My husband had to hold her because I could bear to watch her being zapped. All tests came back clear so we were sent home. Every week we were at the doctors or hospital 4-5 times a week. Every time being sent home with no answers.
At night [redacted] had to sleep upright on my chest because as soon as you laid her down she stopped breathing. My husband worked nights and we had a 18 month old too so I never caught up with sleep. She would only drink a few ounces of milk a day as she had difficulty swallowing but as she was still putting on weight I was told she "just didn't like eating".
Relating to the sleep the doctors diagnosis was she didn't like sleep. At 7 months of still no sleep or answers I persuaded the doctor to work out her dosage for phenagin as I was exhausted and needed some sleep. This allowed [redacted] to sleep for 20 minutes at a time rather than 10. We continued to push the doctors and hassle them into more tests.
At around 2 ½ [redacted] was referred to another hospital for a CT scan to determine whether she had Tracheal Stenosis. This scan revealed that she actually had the vascular ring. I remember the exact words the surgeon said "We are glad we did the scan but it is not tracheal Stenosis, it is a life threatening heart condition that should have been detected during pregnancy and should of been operated on before [redacted] was 3 months old. She is lucky to be alive!" With this she was referred straight to another hospital for further tests and was put at the top of the surgery list resulting in surgery within months.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?
When we heard the news I was devastated but also angry that I was fobbed off and not listened too. I wandered why us. I remember driving home sobbing wandering what was going to be the outcome

Has your child received treatment or surgery?
Yes [redacted] was treated as soon as was possible after diagnosis. The team at the royal Brompton are fantastic. They listened and most of all explained everything that was going to happen. We couldn't of asked for a better team to treat our child.

How is your child now doing now? How are you feeling and coping?
[redacted] is doing very well now. She still gets worn out during games and PE lessons but she doesn't let her past ill health stop her trying. At 7 she was diagnosed with tracheomalacia which we feel she also had from birth but was hidden with the other condition. She has outgrown this but I feel this may have some effects on her breathlessness

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?
This shouldn't be a campaign! They should be tested anyway. Why should so many families suffer like we did when simple tests can prevent a lot of stress on families and children. You only have one heart and you can't live without one so why are babies being put at risk by not being tested.
Received: Thu 05/09/2013 15:15

Pulse Oximetry Campaign – telling your story

Information about you

[redacted]

[redacted]

Information about child

[redacted] aged 6 dob [redacted]

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

[redacted] was just 6 when we told she had an atrial septal defect we found out on the [redacted]. She was never tested & is being monitored by the hospital to have an appointment for a year's time!

[redacted] was another hospital for a bowel problem I spoke to the consultant there who was treating her but he just said it was to do with her bowel problem. I knew her going blue around the mouth & the tiredness & poor apatite wasn't right but when you're told by a consultant it's nothing to worry about you do tend to believe them. I did go to the doctors but was told it was nothing to worry about then in April this year. I insisted he refer her to the other hospital his secretary forgot to send the letter until I kept asking where it was the letter was sent in July.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

Finding out has been totally devastating. How can professionals keep not taking me seriously? I knew my little girl wasn't well. Our lives have changed forever we can't see if her hole is getting bigger we are left in total limbo we know we can ring the hospital for an appointment. How do we actually know without coming across as paranoid? My whole family are devastated. The school and the Children's Heart Federation have been amazing and supportive.

How is your child now doing now? How are you feeling and coping?

[redacted] is doing well there are things in place so we all know what will happen if she gets ill or breathless etc. She will properly have an operation in the New Year so the hole is usually closed by the time they start school. [redacted] has been amazing so incredibly brave & understands and loves the book they sent from CHF.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

I think this campaign is brilliant & we would love to help in any way we can. At the end of the day parents know there kids and doctors should listen to the parents instead of making us feel paranoid and like we're wasting their time. [redacted] 's heart condition should have been detected 2 years ago the hole may of been smaller but more importantly we would of known.

Received: Thu 05/09/2013 20:29

Pulse Oximetry Campaign – telling your story

Information about you

Name: Mrs [redacted]
Address: [redacted]

Information about child

Name: [redacted]
Age: 2
How old when detected: 5 days old
Heart condition: Mitral valve Stenosis, coarctation of the aorta
Treatment received: coarctation repair, closure of the pda
Tested for heart conditions at birth? No

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

Yes my mum and I both noticed [redacted] was feeding very poorly, also she was a bluish colour on from her chest down and making extra effort to breath.
I raised my concerns to the midwifes and dr's in the hospital where I had [redacted] and were assured she was completely healthy, and so we were sent home, as my concerns grew I again raised my concerns to my community midwife whom told me [redacted] most likely had colic.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

We first learnt of [redacted]'s CHD when we took her to our local hospital and the in house cardiologist diagnosed her with severe mitral valve Stenosis.
I think I speak for our whole family when I say our whole life crumbled and this was only the start.

Has your child received treatment or surgery?

Yes, [redacted] has had multiple stays at the hospital where she had a coarctation of the aorta and a closure of the PDA, and she is also awaiting open heart surgery for a mitral valve replacement.

How is your child now doing now? How are you feeling and coping?

[redacted] is fairly well at present despite her other disabilities, [redacted] has to be cared for around the clock and is very complex.
We all just take one day at a time, but I feel I've now come to terms with [redacted]'s CHD whoever none of which would have been possible without my mum who is [redacted]'s carer.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

I personally think this is a must and should already be being used. As I am a mum who knows first-hand how things could be so different if this one small test is carried out at birth, as by the time [redacted] was taken to hospital the doctor's said [redacted] would have had only hours to live if we hadn't of gone on our gut feeling that something was wrong and taken her when we did.

Received: Thu 05/09/2013 22:39

Pulse Oximetry Campaign – telling your story

My details (mum)

[redacted]

[redacted]

Information about my daughter

[redacted]

Just over 1 year old

She was 13 days old when the heart defect was detected. She was in complete heart failure. We found out she had extended coarctation of the aorta, large VSD

She had her open heart surgery at 15days old Tested for heart conditions at birth? No

Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?

(Just a brief of the full story)

After birth [redacted] wasn't feeding properly and constantly falling asleep. She had low glucose + jaundice. We noticed her heart racing and odd breathing which we brought up on a number of occasions but I was blamed for being unable to breastfeed and that newborn babies have sporadic breathing. Our daughter was being closely monitored by pediatricians due to a minor kidney/bladder problem, but we were given the all clear and sent home!

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?

We found out our daughter had a heart condition after 2 doctor trips after a very bad night and i had a mothers instinct of knowing something wasn't right! At second app the doctor thought she had a urine infection but she started turning blue we were blue lighted to our local hospital by that stage she was completely collapsed with no femoral pulses and still not knowing what was wrong.

After a traumatic time (it felt like hours) we were told [redacted] had coarctation of the aorta which we had never heard of. I have never experienced stress, worry loneliness like I felt that day! After [redacted] was stabilised we were blue lighted to a children's hospital where at 15 days old she had her surgery.

Has your child received treatment or surgery?

Yes open heart surgery at 15 days old

How is your child now doing now? How are you feeling and coping?

Our daughter is doing brilliant heart wise with regular check-ups and has been free from heart medications for a few months. We have to visit our local children's hospital regularly for her small kidney issue and I hate going there is always a complete mix of emotions and getting flashbacks.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

It is a brilliant campaign that *needs* to be a standard procedure in the UK! I also feel very strongly about midwives need to look into certain feeding issues a lot more

Received: Thu 05/09/2013 13:52

Pulse Oximetry Campaign – telling your story

Information about you
Name: [redacted]
Address: [redacted]

Information about child
Name: [redacted]
Age: 8 months
How old when detected: 2 days old
Heart condition: Transposition of Great Arteries
Treatment received: Arterial Switch, Balloon procedure
Tested for heart conditions at birth? /No
Additional information

Did you notice that your baby was unwell before her/his heart condition was diagnosed? If so please provide information about their symptoms and if you raised it with any health professionals?
I did think it was strange that she slept the whole time, wouldn't drink any milk and couldn't be woken, but she was barely a day old and she was my first baby. I thought it must be normal, this is what newborns are like. The midwifes came in and out of the room and no one seemed concerned. They commented that she looked blue, but one dismissed it as wind, and another said it was the lighting in our room. They said that it could be due to the fact I had pethadin that she was so sleepy.

Could you describe how you found out that your child had a heart condition? How did you feel, how did others in your life feel?
I had [redacted] on the Monday, both her and myself were 'well' and able to go home. We only stayed in overnight because there had been heavy snowfall during my labour and the motorway was closed. We stayed overnight and all of the Tuesday. The roads were starting to clear and so we packed up to leave late

Tuesday afternoon. They were a little short staffed due to the snow and as there was no hurry for us to leave she slowly had checks done throughout the day like the hearing test. The doctors had checked [redacted], ready for us to leave. They said it sounded like she had a slight heart murmur. Nothing to worry about. Very much played down. Quite common. She said we might just have to come back in 2 weeks. We packed up to go and all that was left to do was take her blood pressure. The nurse took [redacted] along with her father upstairs to another ward where they had the machine. We had been in the basement all this time where the lighting was odd I guess. When they got upstairs, one of the doctors said that she looked a little dusky, and she would like to check her oxygen sats. She said that she expected it to be in the mid 80s as she looked a bit blue, when they checked them they were in the 20s. She was then rushed to nicu. [redacted] then came downstairs with the midwife and said that [redacted] was unwell, and that they were having to help her out with some oxygen. They said they were stabilising her and Id be able to see her soon.

I was taken into a parents room and the doctor came in. He spoke so slowly, all I remember is how he paused in between each word, it seemed so dramatic, like something from a TV drama, I wanted to shake him and get him to spit out what was wrong with my baby. I wanted to know if she was going to be okay , if she was going to die, I wanted him to hurry up but I was terrified of what was coming at the same time. He said "there is something wrong with [redacted], we think it's her heart" It felt like someone had ripped my stomach out, and I was shaking so violently. I thought I might throw up and pass out all at that one time. He told me that he had some idea of what was perhaps wrong but that she needs to go to London to be looked after by specialists. He said they have different equipment and they will know more. He seemed reluctant to say what he suspected. He was going to arrange for her to be transferred asap. When I was taken through to nicu and I saw her I couldn't believe she was my baby. I had just left her in her lovely little going home outfit, she was in my arms sleeping, and now she was naked, her nappy cut back, with tubes and wires everywhere, a machine breathing for her, in a knitted bonnet, in a plastic box. This wasn't my baby! It was like a nightmare. I thought I had a 'normal' healthy baby I was taking home, I hadn't prepared for this. I thought if nothing got picked up during your pregnancy or after the baby is born, you were home and dry. All fine, off home to enjoy the rest of your life as a new family! I felt helpless, they were lots of nurses and doctors doing things to the machines. Talking about her, about things I didn't understand. I felt like I shouldn't be there.

I walked out and back down to the room I had been in. I just fell to the floor sobbing. I looked at the nappies and her things in the hospital bag and I wanted it all gone. I told my mum I didn't want to take it, It was all a constant reminder of the baby I wasn't taking home.I was already preparing for the worst The nurse asked me If I had a memory box for her, because I would need a big one. I didn't know what she meant. I thought is she telling me I'm going to lose my baby? Is she dying? Next thing I knew the St Johns Ambulance retrieval team were there along with a doctor and nurses from another hospital. He told me that he was pretty sure what was wrong with [redacted], but he couldn't confirm until they scanned her on their equipment at the other hospital, and that if it's what he thinks, it can be repaired. She was blue lighted there and we followed in our car.

Has your child received treatment or surgery?
Yes she had OHS a week after she was born.

How is your child now doing now? How are you feeling and coping?
She is doing so well. Her heart is functioning well. There are a few things that need to be kept an eye on and monitored, but they are very happy with her. We are so thankful, happy, relieved, and blessed. We have been very lucky. Of all the heart defects, TGA is said to be the 'best' as her heart had all the right parts, just plumbed in wrong. It can be repaired. The surgeon said there are babies in at the moment that have parts missing, and may not be able to be 'fixed.' He said [redacted] should go on to lead a perfectly normal and healthy life. We are very aware of how lucky we have been and thankful to the amazing doctors and nurses and surgeon that saved her life.

What do you think about CHF's campaign to get all babies in the UK to receive the Pulse Oximetry testing?

It is a no brainer! The equipment is already in the hospital. It is cheap, and painless. Why is not already done?! It simply must be done. We were lucky, it shouldn't be down to luck.

Received: Tue 26/11/2013 20:02

Children's Heart Federation ePetition

The link, below, lists all of the 4426 signatories from the Children's Heart Federation ePetition that called upon the government to roll out pulse oximetry screening in newborn babies in the UK

https://www.dropbox.com/s/yib7pabcleuwxxx/Pulse%20Oximetry%20Screening%20For%20All%20Newborns.pdf

NB: The pages below represent all the consultation responses received as a result of the CHFED campaign and using the CHFED template response, with around half of the responses adding their personal stories of how congenital heart disease has impacted upon them

Responses Linked to

Children's Heart Federation Campaign

1.

Dear John Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in newborns.

Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 each year. Unfortunately only a third are detected before birth, leaving many babies undiagnosed for weeks; often waiting until they are seriously ill before it is recognised. Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

The NIHR Health Technology Assessment on Pulse Oximetry provides evidence that the test increases detection to over 90% of life-threatening congenital heart defects at birth. The research also showed that one in five hospitals successfully offers the test as part of their newborn checks.

Universal screening using Pulse Oximetry has been adopted in many other countries including: the United States and Switzerland and many parents in the UK have joined the campaign to have it implemented here.

With children in the UK still dying from undiagnosed heart defects, I would urge you to recommend that universal Pulse Oximetry screening is introduced across the UK as soon as possible; to give children with heart conditions the best chance for life-saving treatment.

My nephew who is now 4 years old was born [redacted], after a couple of hours of him being alive he was taken to the ICU at fairfield hospital in Manchester, due to breathing problems, after a week of him being in a coma, awake and then allowed home he was diagnosed with a heart defect called hypoplastic-left-heart sydrome (HLHS), which basically means that the left side of his heart didn't develop properly, the week of not knowing was heart breaking for the whole family, and no body knew what to expect, when he was sent home from the hospital a second time in that first week, we were put at "ease" by a doctor who said that he had been put into the ICU because of a lung infection and it was just an after effect, luckily my sister took action a few days later when she felt something was still not right and took him to A&E where it was discovered he had HLHS and was taken to Birmingham children's hospital for the first of three open heart operations. Luckily we now know, and he is doing as well as he could be, and has just come out of birmingham childrens hospital following a cardiac catheter, to check on him for his third open heart operation. However, if the pulse oximetry screening test was there as one of the checks on babies when they are first born, then we would of found out about his HLHS earlier

which would of saved a lot of worrying, and him struggling to stay alive . Luckily for us our story has a somewhat happy ending, because he is still here with us, and we know he is well, but this is not always the case, unfortunately for many other families, they loose their children because they don't find out about their babies heart defects earlier.

Please, make this a mandatory test on new born babies, it'll save a lot of heart ache. Thank You

Best wishes,
[redacted]

2.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I would like to add that this simple test would have helped when my first grandchild was born. Within hours of my Grandson being born, he was taken away to PICU as he was having difficulties in taking his feed and breathing. He was put under sedation as they thought he had a lung infection. He was brought round a week or so later to be sent home, only for the same to happen again. After being taken to Manchester children's hospital, he was then further rushed to Birmingham Children's PICU for emergency open heart surgery.. it transpired he had infact been suffering heart failure and was left undiagnosed for over a week. His diagnosis was hypoplastic left heart syndrome... something a simple oxygen saturation test would have detected. I consider myself one of the lucky ones.. [redacted] did get diagnosed and received the necessary emergency treatment,(still ongoing and has just had a cardiac catheter before his 3rd open heart surgery in the new year) ..but it still could have happened sooner, if only the one of the standard newborn checks was a Pulse Oximetry test. Please don't let other children die .. please make the test standard.

Best wishes,
[redacted]

3.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I was lucky enough to have my daughters heart condition (HLHS) detected before birth, and she was transferred to the children's hospital at one day old. Her oxygen saturations at that point were well below normal at 85-90 % and if the problem was not already known, a Pulse Oximetry test would have been a clear indication that she needed further tests.
Universal screening using Pulse Oximetry has been adopted in many other countries including: the

United States and Switzerland and many parents in the UK have joined our campaign to have it implemented here.

Best wishes,

[redacted]

4.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My own son was diagnosed post natal at nearly 24 hours old with Truncus Arteriosis Type II. By the time it was detected he had begun to fail and eventually had multi organ failure. Thankfully emergency intervention stabilised him enough for surgery at 5 days old with only a 15% chance of success. Had all of his organs not failed his chances would have been much higher. His organs failed due to a lack of oxygen which would have been detected had his sats been checked sooner. He also spent longer in hospital because of these avoidable complications.

My son was saved because of the due diligence of a paediatric doctor who thought she may have heard a murmur during our discharge check. By the time stats and echos were considered he was blue and had a heart rate of 50/38. Obviously pre natal diagnosis at this time is a pipe dream but if a sats monitor reading could have been done sooner my son would have been saved a lot of distress, pain and suffering as would his extensive family and friends who are still traumatised by the memory of what he experienced in his early months.

I hope that the many personal stories you will no doubt hear will move you to make the correct decision morally even if it is contrary to the monetary one.

Best wishes,
[redacted]

5.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

6.

Dear John Marshall,

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My 5 year old daughter was diagnosed with a form of SVT. Although rarely life threatening her heart rate regularly reach 300 beats a minute. We have to take her to hospital and go through the trauma of watching the Doctors try and bring her heart rate down. On a couple of occasions the have struggled for nearly 5 hours to try and control her heart rhythm. It leaves her exhausted and she has a constant fear of hospitals and even the local GP surgery.

I think any heart defect in children, whether life threatening or not, is awful and if anything can be done, it be should be done.

Best wishes,
[redacted]

7.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My own daughter was diagnosed with CHD at 3 years old, I cannot explain in words how devastating it is. Being told that your child, who you had thought was perfect and healthy, has to have major heart surgery. This simple test will save so many families the heartache we felt and they will be more prepared to face and understand the difficulties this brings.

Best wishes,
[redacted]

8.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter was undetected for 2 and a half years. We were told that she didnt like sleep or food when we constantly in the doctors 3-5 times a week. She was in and out of hospital with No answers. At night she had to sleep upright or she would stop breathing and was still on baby food until her surgery age 3. After many tests she was picked up at age 2 1/2 as having a vascular ring with a left abbarant subvlavian artery and we were told she was lucky to be alive. This condition should of been picked up earlier and she would not of had all the suffering

Best wishes,
[name]

9.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I know this all to well because my daughter went undiagnosed for 2years. The stress of not knowing why your child is ill is so difficult. My daughter's CHD should have been picked up at my 20week scan due to the shape of her heart and her ASD but wasn't. At birth she was very blue but was not tested and if she had have been we would have known about her heart condition and life would have been easier.

I feel this is such an easy test that will make such a difference to children and there families.
Best wishes,
[redacted]

10.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

11.

Dear John Marshall, Evidence and Policy Lead

I am writing in response to the Children's Heart Federation's petition and the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in newborns for all babies to receive Pulse Oximetry testing at birth to detect heart conditions.

My granddaughter was born at 6lb 7oz and was not putting on enough weight in her first 4 months Her mother had to stop breastfeeding and was given extra 'strong' prescribed free readymade in bottles formula milk from about 1 month, but the doctors did not seem to suspect anything major was wrong. She stopped breathing at 4 months (thankfully at bedtime so her mother was with her) and her mother revived her with mouth to mouth. She was taken to The Royal London Hospital where the same thing happened again and she was then rushed to Great Ormond Street hospital, was put in intensive care and had an operation to correct **complete atrial ventricular septal defect** two days later. Great Ormond Street doctors and nurses (and The Royal London Hospital staff) were wonderful and our thanks go out to all of them.

She is now 4 and all is well. However, if she had had pulse oximetry testing at birth or soon afterwards I would hope that low levels of oxygen in her blood would have been detected and a heart condition would have been investigated.

I do not want other babies with heart defects at birth to be overlooked. I am aware that pulse oximetry testing is very simple as I have had it done myself.

Kind regards
[redacted]

12.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with heart defect that was undetected. We were so very lucky that we got snowed in the hospital so had to stay in, so we were at the hospital when her cyanosis set it. As we were packing to leave one of the doctors said they wanted to take her upstairs and check her oxygen sats as she looked a bit blue. This saved her life. She was blue lighted to intensive care in the Evelina and stabilised. He was fortunate enough to be operated on when she was just one week old. We are very lucky to have our daughter. Please don't this be left to luck for others. Give children with heart defects the best chance in getting the help and treatment they need.

Thank you so much
Best wishes,

[redacted] and [redacted]

Mother to the wonderful [redacted] - Heart Warrior

13.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

14.

Dear John Marshall,
When our son was born at home in march this year we had no idea he had a complex and deadly congenital heart defect. He managed for just over 2 weeks before I noticed something wasn't right, took him to see our doctor and got rushed to A&E to be told his heart is failing.
It was only thanks to the very skilled staff at Glenfield hospital in Leicester that our son is still alive. Had he received the pulse ox test he could have received his life saving surgery sooner and woudnt have been put in the danger he was.
Since arriving in Glenfield (we spent 8 weeks there) I have met countless families who have been through similar experiences. None of the families there who didn't find out about their child's CHD had a pulse ox test done. For one family in particular who spent 6 MONTHS chasing doctors, health visitors and midwives it would've saved a LOT of stress as not once in those 6 months did anyone use a pulse oz to test this baby who, by the time he was admitted to hospital, had less than a 50% chance of survival. His heart was so enlarged you could see it through his ribs. A simple test would have avoided this.

I urge you to roll out this simple test across all maternity units and community and homebirth midwives as it is so very crucial in detecting the most common birth defect and biggest killer of babies.
Attached is the standard letter to address the issue.

Thank you

15.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

16.

Dear John Marshall,

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My little boy was born with pulmonary atresia and vsd, I was lucky as it was diagnosed during pregnancy so the medical team were well prepared for when he was born but I hate to think what would fave happened if it hadn't been diagnosed, he certainly wouldn't be here today, I personally think this is a really important test to be carried out in all newborns, it would definitely save a lot of babies lives.
Best wishes,
[redacted]

17.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

In my case, i have had 3 scans during my pregnancy, and my daughter`s problem wasn`t diagnosed in any of them. Luckily i`m a mum of two, so when she started to show signs that something is wrong i took her to the doctors, and she listened. But i can`t help thinking, what if i ignored thinking it`s just colic. She was only 2 weeks old when we found out she has a serious heart problem and our life has turned upside down. Only if we knew earlier.

Best wishes,
[redacted]

18.

Dear John Marshall,

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Personally my son was taken into intensive care at 4 weeks old with undiagnosed super ventricular tachycardia. As I am sjre you can understand this was so traumatic for everyone involved and I truly believe this could have been picked up on sooner causing a lot less distress and medical intervention.

Best wishes,

[redacted]

19.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Personally my son was taken into intensive care at 4 weeks old with undiagnosed super ventricular tachycardia. As I am sjre you can understand this was so traumatic for everyone involved and I truly believe this could have been picked up on sooner causing a lot less distress and medical intervention.

Best wishes,
[redacted]

19.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Kind Regards,

[redacted]

20.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

In November 2012 my son [redacted] was born with a single ventricle heart defect called Tricuspid atresia. Luckily his defect was detected within an hour or two of birth because he had to be delivered by emergency section due to reduced fetal movements. But his cardiac issues, along with various other serious health problems had not been detected at any of my ante natal scans. If left undetected, his heart would have stopped functioning within a couple of weeks of birth and he could have died.

Yours sincerely
[redacted]

21.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

We were lucky enough to find out before our son was born that he had a rare and complex chd. Others are not so lucky! if we didn't find out at our scan we would have taken our son home none the wiser and his heart would have failed. We wouldn't have him alive today! Save lives and make pulse ox mandatory

22.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

This screening is very close to my heart because earlier this year our little boy, [redacted], died very suddenly and unexpectedly when he was just 5 weeks old. [redacted] was our first baby and the first grandchild on both sides of the family. He was a very beautiful, strong, alert baby boy and he was growing and developing well. One day I noticed he didn't feed too well. He didn't seem poorly but just didn't seem to be himself. Later that evening we took him to hospital for a check-up to be on the safe side, we thought we were being over-cautious parents. However when we got to hospital [redacted]'s condition deteriorated very quickly. His heart stopped about an hour after we got to the hospital and he couldn't be revived. Our lives changed forever that day and myself, my husband and our families are struggling to come to terms to life without our little boy.

The post mortem found that [redacted] had a congenital heart defect which wasn't detected - it couldn't be detected on the antenatal abnormality scan and he showed no signs or symptoms of being poorly after birth. [redacted] was with us for 35 precious days, we got to know him so well, his little personality, he was so full of character. Having to say goodbye to him when we had got to know him and love him so much is unbearable and I don't think the shock, pain and emptiness will ever leave us. Please recommend that pulse oximetry is introduced nationally for all babies as routine. If it can prevent one baby from dying from an undetected congenital heart defect and therefore prevent one family from suffering this pain and heartache, then it absolutely must be done.

It is too late for our son, but it isn't too late for others.

Best wishes,

[redacted]

23.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

This is too late for my daughter [redacted] who was born on September 29th 2008 and died 10 days later [redacted] 2008 As her heart defect went unnoticed until it was too late. I was a mother of 2 children prior to [redacted] and at hospital I had a feeling when [redacted] was born something was not quite right and although the heel prick blood test was done before we left the hospital, this was not what [redacted] needed. Had she of been tested with the Pulse Oximetry, I strongly believe she would be with us today.

I will never know the pain my child went through, but I live without her every day. This is a simple test, that will save many babies and parents the heartache I go through every day.

Please support this amazing cause and save our babies.
Thank you

Best wishes,
[redacted]

24.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My family has first hand experience of a lack of pre natal diagnosis. I had twins in July 2006, both of whom have a form of tetralogy of fallot which sadly was not detected before birth. This was detected only after birth whilst in hospital and it given one of them had his first surgery at 7 weeks, with the time between birth and then being horrendous, we could have been prepared and avoided some of the trauma if we had been able to prepare for what was going to happen.

I am also a trustee of The Brompton Fountain, the parents support charity at The Royal Brompton Hospital. We support parents both pre and post natally and it makes such a huge difference to parents, especially those who may be likely to have lengthy stays in specialist hospitals where their children have not been born, to have a chance to meet other families and tour the hospital ahead of the birth of their child. For many the first few hours and days are vital, and this simple test can not only help families but all evidence shows the prenatal diagnosis and resulting preparations can reduce complications and also save lives.

Best wishes,
[redacted]

25.

Dear John Marshall

Template text removed to reduce file size. See green text above.

We were lucky enough to find out about our daughter's congenital heart disease at my 20 week antenatal scan. When she was born, the medical team were available to take her straight to ICU and the next day perform the life saving surgery she needed. She has since had another heart operation and is due her final one when she is 3. When our second daughter was born we requested a pulse oximetry test whilst in hospital to ensure that her heart did not have any defects which had been missed by the scans. I can not imagine the pain parents feel to only find out about their child's heart condition when they require emergency treatment and this may not be soon enough.

Kind regards
[redacted]

26.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son was born [redacted] 2010 in [redacted] Hospital and this test could have shown that he had a heart defect a lot quicker. His defect was undiagnosed and it wasn't until 6 hours after his birth that he began to present with problems. As I had just had an emergency section with him I was unable to move and had to buzz for a nurse who promptly took Liam from me. He was resuscitated twice before they got him to the neonatal unit and from there he was stablised and sent to the Royal Belfast Hospital for Children which is 25 miles away. This test NEEDS to be adopted in the UK so that the child can be diagnosed and not left to fail and maybe die. The distress that me and my husband went through because our son's condition was undiagnosed do not need to happen with this simple test. I would urge you to make this a permanent fixture as a check for newborns.

Best wishes,
[redacted]

27.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I have an interest in this as my 2yr old granddaughter has borderline HLHS and other serious heart defects and so far has had 3 open heart operations, 1 keyhole and due a fourth major operation in the new year.
Best wishes,
[redacted]

28.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

29.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
Kind Regards,
[redacted]

30.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

31.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

32.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I have a 16 year old Daughter, She was born with TOF, MAPCAs, coronary fistulas & some other complications. She was not diagnosed until she was 10 weeks old.

When my daughter was born she was a bit of a funny colour, yellow/blue, we were told she was probably a bit jaundice but was otherwise healthy. For the following 10 weeks My child struggled to eat, projectile vomited regularly, was constantly either drowsy or screaming the place down, and was generally unwell. I constantly called GP's out and was told on many occasions that I was just being over protective as a first time mum and that it was viral. Eventually my health visitor listened to my concerns and we saw our local GP, she listened to my daughter's heart and sent us to our local hospital. From there we were blue lighted to Alder Hey with a pulse ox level in the 50's.

I cannot convey in words just how strongly I feel about all new babies being given the pulse oximetry test. Such a small test could save people like me from weeks of distress, children like my child could receive the medical help they need straight away, and it WILL saves lives.

I was lucky, I did not give in and accept what I was told, that there was nothing wrong, when there was. We got someone to listen in time, some do not.. I do not want to see anybody go through what we had to. 16 years down the line and I have heard so many people who have experienced similar situations. This needs to stop, and this simple test is the answer.

Thank you for taking the time to read this email, please feel free to respond if you have any questions.

Best wishes
Miss [redacted]

33.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I have an 18 year old daughter with Pulmonary Atresia, who went 'blue' in my arms at 20 hours after her septum closed - pulmonary atresia in her case is complex, and meant she was born with a very small, blocked right side to her heart, so would have died as no blood could reach her lungs. Pulse oximetry from birth would have picked up her falling oxygen saturations, and not left her with a new mother who had no idea what colour her baby should be, and also why she wasn't feeding or crying. My daughter was saved initially by an observant midwife, who thought she had swallowed some sick, so held her in the daylight before whisking her off to the intensive care section of the Surrey hospital we were in, thence onto the Royal Brompton, London, where she had life saving surgery followed by further surgeries at 15 months, 7 years, 14 years and ongoing palliative care.

This is such a simple test that can be done with no pain, and yet can be life saving, so please, I urge you to ensure it becomes the norm.

Best wishes,
[redacted]

34.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
Mrs [redacted]

35.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 each year. Unfortunately only a third are detected before birth, leaving many babies undiagnosed in the neonatal period. Many will become seriously ill before it is recognised. Pulse Oximetry screening can alert clinicians to the possibility of a significant cardiac defect and thereby help to save babies lives, as well as avoiding potential long-term damage to a child and distress to their families.

With children in the UK still dying in the neonatal period from undiagnosed heart defects, I would urge you to recommend that universal Pulse Oximetry screening is introduced across the UK as soon as possible; to give babies with heart conditions the optimal chance for life-saving treatment.

Best wishes
[redacted], MA FRCS, Professor of Paediatric Cardiac Surgery, Evelina London Children's Hospital

36.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My own son was born with severe and complicated congenital heart defects which were diagnosed only by chance the day after he was born, thanks to the diligence of a doctor at the hospital. He was then put under Great Ormond Street Hospital whose specialists were able to diagnose him properly, plan his treatment and reassure us, his parents. After two bouts of open heart surgery, he is now 19 and studying Physics at the University of Sussex.

Best wishes,

[redacted]

37.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Kind regards,
[redacted]

38.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son at the age of 5 collapsed and his heart stopped for 40mins. To cut a long story short he had to learn to walk, talk and eat again. This was all due to a heart disease that had not been diagnosed but was probably there from birth. We are one of the lucky ones as our son is still with us but it could have been such a different story.
Best wishes,
[redacted]

39.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes, [redacted]
Associate Editor

40.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with a Congential Heart Defect or murmur as my GP stated at her 6 week check, in the beginning of August 2009, we were given an appointment to see a consultant at our local hospital for the beginning of November. I mentioned to the GP that feeding was difficult, he suggested that I try bottle feeding rather than breast feeding. Also asking if I was feeling low!
I went back two days later as my daughter had lost weight, he refused to weigh her. Long story short she was admitted into hospital the very next day very very poorly indeed, she had an echocardiogram, which found a small Atrial Septal Defect and a large Ventricular Septal Defect. She had a nasogastric tube inserted as she was too poorly to feed by herself. My daughter had her open heart surgery aged 4 months. Incidentally in the same week that she was due to have her first original

appointment the GP arranged.

Pulse Ox screening is non-invasive and should be included in the examinations that are completed on new born babies. Had my daughter been screened we would have not gone through the trauma that we were subjected to or nearly lost our daughter.

We are fortunate that our daughter is a survivor of CHD, this is not the case for all CHD babies many dying before they can even be diagnosed, this test will save lives.

Best wishes,
[redacted]

41.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter had a congenital heart defect at birth which was not picked up until she was approx. 3 months old, I had a terrible time with her as she just continually cried all the time, she could not take her bottles as she was unable to take anymore than an ounce, she was exhausted after that and I went through the experience of health visitors telling me it was because I was not feeding her properly etc etc until one day one of the nurses from our practice noted that her lips were blue and spoke to my doctor and the very next day my daughter was admitted to hospital and then onwards to Yorkhill Hospital where Dr [redacted] performed an operation on her. She still attends hospital on an annual basis and has since had her own child but I would have felt happier if they had some sort of check in place. My granddaughter has been checked by doctors and appears to be fine but had this been in place it would have put my mind more at rest.

Good Luck with putting this forward, I think it would be a great test for babies going forward, especially if their Mums had this problem.

Best wishes,
[redacted]

42.

Dear Mr Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in new-borns. My son was first identified as bradycardia at 14 weeks in foetus. His neo-natal cardiologist, Dr [redacted] can now detect foetal abnormalities in the FIRST trimester. [redacted] who will be 18 in February, was one of the lucky babies 19 years ago to be able to be tracked through his development in the womb and then post birth, when a further abnormality was picked up, a double aortic arch. As a result, Dr [redacted] who has written the world standard for foetal scanning, included a check for that as part of the standard procedure for foetal scanning.

[redacted] is one of around 5,000 to 6,000 babies born each year affected by a congenital heart defect, which are the most common birth defect. He was one of only a third who were lucky to be detected before birth, leaving many babies undiagnosed for weeks; often waiting until they are seriously ill before it is recognised, as he would have been.

Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

As a mother whose child has survived and thrived (since 1996 with a pacemaker) but

Best wishes
[redacted]

43.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter who was born in Birmingham in 2008 who received a similar test for, luckily she didn't have any problems. It was a simple quick and effective test.

Best wishes,
[redacted]

44.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son was diagnosed with a Ventricle Septum Defect when he was 4 and a half months old, not by his GP in the UK but by a doctor in France whilst on holiday. This doctor and the cardiologist she referred us to straightaway were both surprised that his heart condition had not been picked up before as his systolic murmur was so loud that even during his 8 week check up it would have been heard/noticed. The minute he was diagnosed by the cardiologist in France, he was prescribed medication. When we returned to UK, we saw our GP who then acknowledged his murmur. My son got referred to Queens Hospital and then Great Ormond Street Hospital, where he had his operation on [redacted] 2013 just before he was 9 months old.

Had the two paediatric doctors who gave him a clean bill of health after his birth done this Pulse Oximetry test, his VSD would have been discovered and treatment could have been given immediately.

Had the GP given this test at his 8 week check up, especially when she knew that he was dropping in the centile weight growth chart, his VSD could have been detected and treatment administered accordingly.

I cannot fault the service provided at Queens Hospital and especially at Great Ormond Street before, during and after his operation. But my issue is with how it did **not** get diagnosed and it probably

would have been missed until he was running around and his heart failed him. After the age of one, if left untreated the amount of stress the heart, veins and arteries are placed under is tremendous and any chance of them contracting to the size they should be after an operation is minimal, which would leave the child with various health and tension issues for the remainder of his or her life.

Best wishes,
[redacted]

45.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

46.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

47.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes
[redacted]
Cardiac Adolescent and Transition
Clinical Nurse Specialist
[redacted]

48.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

We represent individuals with heart conditions that also have Down's Syndrome, yet despite the high incidence of cardiac problems in this cohort and very clear guidance from the UK Down Syndrome Medical Interest Group http://www.dsmig.org.uk/library/articles/guideline-cardiac-5.pdf, we still hear

of babies with a late diagnosis of CHD. These families have enough to cope with in the early days and weeks after birth, they do not need the additional stress of believing that their baby has no heart issues only to find a few weeks (or months) down the line that this is not the case.

This is a simple, inexpensive test that could (and should) easily be undertaken on all new babies to dramatically improve the detection rate of CHD allowing time for parents to be informed and further surveillance planned and undertaken as necessary, rather than distressing and potentially emergency situations arising.

[redacted]
Director
Down's Heart Group

Email: [redacted]
Tel : [redacted] | Fax : [redacted] | Skype: [redacted]
Web : www.dhg.org.uk

49.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My niece was just 8 days old when she had to undergo emergency open heart surgery at Southampton General Hospital. She was born with coarctation of the aorta and a had a hole in her heart which remained undetected until she went into heart failure. In just 30 mins she crashed, and was minutes away from the unthinkable. Thanks to the bravery and speed of thinking of her parents and the talents of many medical staff my niece is now a beautiful thriving 2 year old. However the stress, pain and trauma induced on my niece's tiny body and our family could have been reduced if testing was in place for newborns.

Best wishes,
[redacted]

50.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Our son was one of those babies not tested and not picked up until day seven when he became very ill ([redacted] [redacted] DOB [redacted]) – despite having been checked prior to leaving Causeway Hospital, and by 2 community midwife visits. We are enormously blessed to have our son and owe his life to a chain of excellence starting with a swift thinking GP ([redacted]), local hospital (Causeway Hospital) , a paediatric cardiologist (Dr [redacted]) – and a team at Birmingham Children's Hospital. [redacted] was operated on by [redacted] and [redacted]. Dr [redacted] at Birmingham told us that Luke's condition would have been identified in Birmingham, had he be born there. Luke had a hypoplastic aortic arch (severe), large VSD, PDA and bicuspid valve. He is in life long cardiac care. He surgery was very successful. As said, we are very blessed.

Whilst we can never articulate how thankful we are – our small family was in an awful trauma from 27th July, 2011 when [redacted] went blue in the shoulder and thigh. We had no idea – despite this being our second child. It took us months to recover from the trauma, if we ever will, and our first child had to be left with relatives whilst we followed an air ambulance to Birmingham from Belfast. [redacted] (our first child) was very traumatised by the whole experience. So, please, please, please do this test – it might not identify all heart babies yet, but in the meantime it will raise awareness, train the eyes of those administering the test and inform the parent about CHD – all of which are very important. Midwives and parents would raise the money to do this.

Best wishes,
[redacted] and [redacted]

51.

Dear John Marshall

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in newborns

Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 each year. Unfortunately only a third are detected before birth, leaving many babies undiagnosed for weeks, often waiting until they are seriously ill before it is recognised. Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

If this test had been made available to my Great Granddaughter [redacted] when she was born she may not have passed away at eight days old. We thought we had a perfect baby !!!!!!

With children in the UK still dying from undiagnosed heart defects I would urge you to recommend that universal Pulse Oximetry screening is introduced across the UK as soon as possible to give children with heart conditions the best possible chance for life-saving treatment.

Best wishes

[redacted]

52.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I was fortunate that my 20 month old sons congenital heart defect was detected prenatally at the 20 week anomaly ultrasound scan. However, if this had not been the case a minor test such as this would have identified my son's very low oxygen saturations at birth and lead to a more detailed heart echo scan to detect his heart condition. He had open heart surgery at Great Ormond Street hospital when he was 6 months old and may very well not be here now if his heart condition was left undiagnosed.

If this simple test can identify those newborns that would usually go undetected then this is more than worth it.

Best wishes,
Mrs [redacted]

53.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[name]

53.

Dear John Marshall,

I am writing in response to the UK National Screening Committee?s consultation on their policy on Congenital Heart Disease screening in newborns.

Best wishes,
[redacted]

54.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

If my son, [redacted] could have had the test then we would have known about his congenital heart problem. We found out purely by chance that he needed heart surgery at age 3 - he had a life threatening condition which has now been treated.

Best wishes,
[redacted]

55.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

56.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

57.

Template text removed to reduce file size. See green text above.

Best wishes,
[name]

58.

Hi.

Id like to support the campaign for all babies being tested for heart defect before birth. As my boy dies last year at the age of 1 year because he had dilated cardiomyopaty which was undignosed at birth. My son was diagnosed at 5 months when his health deteriorated and was in intensive care on life support machine for nearly seven months. He was refused a heart transplant.

[redacted]

59.

Dear Mr Marshall

Template text removed to reduce file size. See green text above.

Fortunately, we were one of the lucky ones and our son's congenital heart defect was picked up prior to his birth at the 20 week ante-natal scan. He therefore had the best chance possible and thanks to the care we received initially at our local hospital and then at the Evelina London, we are very lucky to have our healthy 6 year old. During our stay at the Evelina, we met many families who were not as fortunate as us because their babies conditions were not picked up until they had become seriously unwell and had to be blue-lighted from their local hospital to the Evelina. Their chances would have been much better if the conditions had been picked up before the babies became desperately unwell. Of course, being a parent of a heart baby is stressful whatever the circumstances of diagnosis, but the situation is made much much more difficult so if the condition is only picked up once the baby is seriously ill and its chances of survival are reducing as a result of the delay in picking up the condition and starting to treat it immediately.

Regards.
[redacted]

60.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My own condition was only diagnosed as I needed surgery for a hernia. Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

Best wishes,
[redacted]

61.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My Son, [redacted] has a congenital heart defect (Hypoplastic Left Heart Syndrome, one of the most severe defects). Luckily his was picked up on a scan before birth, but I know personally quite a few families whose children weren't and because of this their children were very very sick and nearly died, sadly some did die. If this came into practice as standard so many lives could be saved.

Kind Regards
[redacted]

62.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted], was born in 2008. It was a normal delivery without complications. I was in hospital for two days. I was just about to be discharged, and was packed and ready to go home, when a passing doctor thought [redacted] was looking a little blue. [redacted] was taken to intensive care 'for a bit of oxygen' and once on the ward she was diagnosed with Severe Ebstien's Anomaly - a rare heart condition, for which there is no cure. She lived for 16 months. I have been told that [redacted] very nearly went home that day, undiagnosed. She was not displaying extreme symptoms of her condition and we came close to taking a sick baby home, where she may well have died in her first week. Instead she was transferred to Alder Hey Children's Hospital and treated there until she was ready to come home. I believe that if [redacted] had been tested at birth, her diagnosis would have been less traumatic for me and my family. For two days, I thought I had a healthy baby and I was wrong. It was such a distressing shock to discover her condition. If diagnosed immediately at birth, [redacted] would have been transferred quickly and her care started sooner.

Best wishes,
[redacted]

63.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My 4 year old son was born with Transposition of the Great Arteries, Pulmonary Atresia and VSD. He was born in Abu Dhabi, UAE and was thankfully diagnosed at two days old before we had left the hospital but it fills my heart with dread to think that some babies could have a life threatening heart codition that goes undetected and they are discharged from hosital with a ticking time bomb that could do irreperable harm to them at any time. My son has had 3 operations and is thankfully doing very well.

Best wishes,
[redacted]

64.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Our story
Our son, [redacted], now, thankfully a happy and thriving 3.5 year old was born via emergency c-section at 38 weeks. At 6 weeks old and after many frantic visits to our GP/home visits from our Health Visitors (during which I was told that [redacted] was perfectly healthy and normal to be extremely restless) [redacted] was finally diagnosed with SVT in our local hospital.

I had raised concern about [redacted]' erratic breathing and mouth breathing to a number of medical professionals since he was just a few hours old only to be told that he 'looked' perfectly normal. It was only on returning to our local Hospital and from my belief in my mummy instinct that we were finally found to have a heart problem and [redacted] started to receive the most excellent care from his cardiologist. It is thought that [redacted] was in and out of prolonged SVT since birth as his left side of his heart was deflated so we received urgent care for 5 weeks in PICU/High Dependency. Even when [redacted] was only a few hours old I sensed there was a problem, yet my concerns on the maternity ward were not listened to and I was considered to be a nervous new mummy. Had [redacted] have been fortunate enough to have a Pulse Oximetry screening test in hospital his condition would have been picked up by the most experienced Dr's who could have helped prevent [redacted] suffering with SVT for 6 weeks. Please help to protect our previous babies by making Pulse Oximetry Screening compulsory, we are one of the lucky families who's precious son is now receiving ongoing care but we need to protect as many babies as we can from CHD and the sooner any problems are found the more likely we are to save/protect little hearts. There is no question here, we need to make this standard health check for newborns. Thank you for reading a very brief summary of our experience. Only recently have I have been able to even say SVT without breaking down, this is so important to us that children are protected from CHD/heart problems in the future. Thank you. [redacted]

Best wishes,
[redacted], [redacted] and [redacted]

65.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[name]

66.

Dear Mr Marshall

Template text removed to reduce file size. See green text above.

I have blogged a little about my own story
here: http://soundinglikemymother.blogspot.co.uk/2013/11/anniversaries.html

Kind regards

[redacted]
67.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

On a personal note, my grandson was born with severe undiagnosed heart defects and was almost discharged despite being blue. It transpired that his heart was on the wrong side of his body, back to front and did not have "plumbing" between the heart and lungs. Fortunately at under a week he had a shunt fitted and after further life threatening operations he is now four, at school and thriving. If he had be diagnosed before birth, great trauma to him, his parents and wider family may have been avoided.

Best wishes,
[redacted]

68.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I nearly lost my son [redacted] to a heart condition that was not picked up at either pre-natal or post-natal checks. We noticed he was ill when he was born but he was treated for a lung infection and sent home. When we got home he was cold and always sleeping. We rushed him to hospital where he was finally diagnosed with a heart condition.
Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 each year. Unfortunately only a third are detected before birth, leaving many babies like [redacted] undiagnosed for weeks;

I think this campaign is amazing. I cannot express how important it is for this to go ahead. I nearly lost my baby, so many times, and this could have been prevented just by one simple test when he was born.

Best wishes,

[redacted]

69.

[redacted]

2nd December 2013

Dear John Marshall,

Template text removed to reduce file size. See green text above.

In fact, this happened to my first daughter who was not diagnosed with a heart murmur until she was six weeks old.

Best wishes,
[redacted] and [redacted]

70.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,

71.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

72.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted]'s heart defect was diagnosed at 3 weeks old due to a very experienced health visitor insisting she was sent to hospital for a check up. This was after 3 weeks of voicing concerns to the midwives and listing symptoms that I now know are the signs of a heart defect. In no way their fault with all the babies and mothers they see with concerns however if a test was available in hospital it could have been picked up straight away and [redacted] would have received the appropriate care from day one. Had my health visitor and the hospital not been so diligent we may not have her with us today.

Best wishes,
[redacted]

73.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son would be an example of this.

When my son was born, both my partner and I had a gut feeling something was wrong. His breathing was heavy, his hands and feet very blue, but doctors and midwifes assured us he was fine. three weeks after his birth I rushed my baby into A&E with breathing difficulties. A day later he was diagnosed with a large VSD and an ASD. His vsd was a centermetre long. It was decided surgery would be at 3 months old. However From that point my son became very ill in the period of two weeks and at five weeks old I had to send my first newborn child down for open heart surgery.
My sons VSD was so large, it should have been recognised in my 6 month scan. However it wasn't. But if this simple Pulse Oximetry test was done at birth, it would have been detected then. And possibly prepared us for what was about to come.
Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

Kind Regards
[redacted]

74.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter has had health issues since birth (low birth weight, interrupted feeding projectile vomiting, acid reflux, anxiety,) After seeing a Dietitian and having many tests for these problems it was not until she was 11 when my daughter insisted that there was something wrong with her heart that we insisted that the GP check her heart. He did and discovered a heart murmur. He said she would grow out of it !!!!!! I then took her for a second opinion and we then ended up at Alder Hey for a Echo Cardiogram where an AVSD was diagnosed. An operation was then urgently arranged.

If Pulse Oximetry had taken place when [redacted] was born it could have enhanced the quality of my daughters young life and prevented a possible fatality. She is very lucky that she has survived to her diagnosis and I am still considering whether to sue the Trust or not.

What a lot a little can do!

Best regards,
[redacted]

75.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

76.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

77.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I myself am a GP, and in December 2013 my son was born with Transposition of the Great Arteries, a condition which can leave a baby looking quite normal and stable at birth, without a heart murmur necessarily. These children can therefore be sent home with no idea that within 24 hours their child may well acutely deteriorate into crashing heart failure and need emergency surgery to save his/her life. Fortunately my son was diagnosed ante natally but we met a number of families in Alder Hey hospital who had not been so lucky and who had been discharged after birth with no idea that their child had a problem. By the time the problem is detected, the child is in a very poor condition and surgery becomes higher risk and more urgent.

As a GP who regularly sees newborn babies and performs neonatal checks I know that checking oxygen saturations is not part of the routine 6 week screening done. Therefore children would not even be picked up at this point. They need to be recognised and managed appropriately from birth, and in this day and age, a simple, easy to use and very affordable piece of equipment, a pulse oximeter, should be available on every delivery suite/postnatal unit and routine measurement of oxygen saturations incorporated into the routine neonatal checks.

Best wishes,

Dr [redacted]

78.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born with TGA, undiagnosed until he was born. The condition was picked up because he had bilateral talipes (which WAS diagnosed ante-natally) and I requested a paediatric consultant review before discharge from hospital. He looked an odd colour and was breathing fast. The midwives said he was 'bruised from birth' and that babies breathe faster! I had to insist he was seen. Thankfully the paediatrician did a 'SATS' test, leading to a quick diagnosis. But what a simple test – it could have been so easily done by the midwife.

I was horrified to learn how many babies with congenital heart defects are left undiagnosed for weeks; often waiting until they are seriously ill before the defect is recognised, with an massively increased cost to the NHS – reapeated visits to the GP and then additional care required when they are finally diagnosed, as they are so much more difficult to treat. And yet Pulse Oximetry screening is so simple, the machines are relatively cheap. How can it not be carried out routinely when it can help to save babies lives, avoid needless long-term damage to a child and distress to their families, and save costs for the NHS?
Universal screening using Pulse Oximetry has been adopted in many other countries including the United States and Switzerland and many parents in the UK have joined the campaign to have it implemented here.

Please please let sense prevail in this matter.

Kind regards
[redacted]

79.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

In 2010 My son [redacted] was diagnosed a few hours after his birth with a very serious heart condition. He was having open heart surgery at Great Ormond Street within hours and during his 29 days he fought to stay with us he endured two more open heart surgeries, a Ross Procedure and countless other procedures. With the severity of his condition it really should have been detected earlier to help both ease his and our distress. It is impossible to put into words how his loss affected us.
We were delighted to have been blessed with a second child, [redacted] who is now six months old. We got fantastic screening with her but it infuriates me that you have to endure such a loss to ensure you get great care. Thankfully [redacted] has a very heathy heart. I really feel that all babies should be offered screening for heart defects though seeing as they are often undetected until a serious problem arises.

Best wishes,
[redacted]

80.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

81.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

82.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

83.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

From personal experience not finding out about my baby's heart condition until they had crashed and had to have life saving heart surgery when they were only hours created a very worrying and difficult time for my husband and myself. Listening to the Drs talking about percentages of survival and then brain damage, risk of this and that, is not what new parents want to hear, it was an extremely emotional time. My heart warrior condition was picked up as soon as they put a probe on him and his SATs level were so low that they then did an echo and discovered he had Transposition of the Greater Arteries. A rare heart condition that effects 1 in 10,000. He went on to have open heart surgery at 5 days old that saved his life. He is a miracle and will continue to be monitored for life as he also has a hole in his heart and now has leaky valves from the arterial switch operation that was performed. When my heart warrior was born he was blue and was given oxygen, he did not have the pulse test at this point, which would of helped him from getting worse over the following hours. A mothers instinct told me something was wrong and I kept telling the nurses 'He is a funny colour', so was given oxygen again. Later when he was in major distress, did a nurse say 'I don't like his colour' and the Drs checked him over again. To me this small simple test should be compulsory. To save other parents going through hell and back with their newborn on the most special day of their lives.

Best wishes,
[redacted]
Heart Mum

84.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Thank you for your attention.
Yours sincerely,
[redacted]

85.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My Son was born with an undetected heart defect in 2010. From the moment he was born his colouring wasn't right although when questioned with the paediatrician I was told was normal as it can take a while for the circulation to get going. We were discharged even though I wasn't happy with his colouring and the next morning when the midwife came to visit she called an ambulance straight away. By the time we'd reached the hospital my Son needed to be resuscitated but fortunately thanks to the quick reaction of the team he survived. Unfortunately our eldest Son (who was 3) witnessed the events unfolding and the team of 10-12 doctors working on his little brother as obviously we weren't prepared for this and had no childcare. He was diagnosed with a Pulmonary Atresia and had open heart surgery the next day at the Birmingham Children's Hospital. Today he is a healthy and happy little boy who will need surgery again at some point but his scar reminds us of the trauma of his first few days of life. Ultimately having the Pulse Oximetry screening wouldn't have changed the fact that he needed open heart surgery but if this test was part of the newborn screening checks then his treatment would have been from his first few hours of life and the start of his life wouldn't have been so traumatic. As he needed to be resuscitated we faced the uncertainty of him being brain damaged but again thankfully he wasn't. What should have been a very happy occasion was destroyed for us and if a simple test can help to prevent the added trauma for any parent then I would urge you to bring in the screening for all newborns.

Best wishes,
[redacted]

86.

Dear Mr Marshall

Template text removed to reduce file size. See green text above.

Congenital heart defects are the most common birth defect affecting around 5,000 to 6,000 each year. Unfortunately still only a third are detected before birth, leaving many babies undiagnosed for weeks; often waiting until they are seriously ill before it is recognised.

In March 2000 I gave birth to our second son, [redacted]. On the day that I was being discharged from St John's Hospital, Chelmsford, my husband and I noticed that [redacted]'s hands and feet were going very dark blue when he cried. After we highlighted this the NHS showed what they are made of, and there were doctors and consultants rushing around to his aid. [redacted] was transferred to Great Ormond Street Hospital where there was a medical team awaiting our arrival. [redacted] had transposition of the great arteries and was very ill until he received a 'switch' operation. The oxygen levels in his blood went down to 30%.

Pulse Oximetry screening can help to save babies lives, as well as avoiding needless long-term damage to a child and distress to their families.

Universal screening using Pulse Oximetry has been adopted in many other countries including: the United States and Switzerland.

I am sure you will be pleased to know that (because [redacted] has parents who happened to notice the colour of his toes) he is 13 years old and was awarded a place at Grammar school. We are very proud of him and want to ensure other parents get the chance to be very proud of their heart babies and that their condition does not go undiagnosed.

I have written to my MP, John Whittingdale OBE urging him to support this test. In his response dated 18th November 2013 he informed me – '….Currently, the UK National Screening Committee is reviewing the results with a view to making a recommendation early next year. I will of course await the outcome with interest'.

There are very many people who passionately support this test and will be eagerly awaiting the outcome.

Yours sincerely
[redacted]

87.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

88.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son was born in July this year in Leeds and through the pulse oximetry tests they found he had a critical heart problem - a coarctation of the aorta and small valves on the left side of his heart. He was able to quickly receive the care he needed and had an operation at 10 days old. Without the pulse oximetry tests we probably would have taken him home and he would have gone into heart failure. I thought I would share my story with you to see if it could help at all with the pulse oximetry campaign. I have had everyone I know sign the petition about this as we feel it is incredibly important.

Best wishes,
[redacted]

89.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My son [redacted] was born in May this year with a hole in the heart Ventricular Septal Defect (vsd) this was undiagnosed until his eight week check.He is now awaiting open heart surgery at Great Ormond Street Hospital.
Kind Regards

[redacted]

90.

Heartline Families is a Charitable Incorporated Organisation supporting children with heart disorders and their families, whatever the condition, wherever it is treated throughout UK and Ireland.

Please excuse this brief contribution to the consultation – I have read the documentation, and as a member of Children's Heart Federation would wish to associate Heartline Families with that response.

I would like to add that should additional pilots be run, this should be concurrently with universal adoption of PO screening – delay will be measured in mortality and morbidity, not in clarity of data.

There is little about the cost to families of late diagnosis of heart disease in children, whether critical or significant. The emotional cost to parents is very high. There is a degree of preparedness for a diagnosis soon after birth when tests are being carried out. Those whose children have 'failed to thrive' because of an undiagnosed heart condition (and where a diagnosis is left to a perceptive HV or GP who can overcome an assumption of an incompetent or overanxious mother) have their confidence in their abilities to protect and nurture their child undermined. If the financial cost of providing additional screening and diagnostic services are to be reckoned, I suggest the cost of anti-anxiety drugs and counselling to relieve the stresses these families encounter should also be calculated.

Kind Regards
[redacted]
Chair of Board of Trustees
Heartline Families
[redacted] Web: www.heartline.org.uk
Tel: [redacted]

91.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My own son was born with a congenital heart defect and I was very fortunate that it was detected at my scan. I dread to think what might of happened had it not of been detected. As it was I was given the best care throughout my pregnancy and we knew what to expect and the hospital were ready for us when he was born. We were able to talk and explain it to our other 3 children so they could try and understand.

Although it was still very distressing at the time I am so grateful if was detected so we had time to prepare and gain knowledge on what was ahead.

This is why it is so important for this screening as not all parents are as fortunate.

Best wishes,
[redacted]

92.

To John Marshall

Template text removed to reduce file size. See green text above.

My grandson, [redacted], was born [redacted] 2010 with Transposition of the great arteries. This was undiagnosed and he got to 2 days old before showing main symptoms; symptoms noticed (purple feet and mouth) were put down to immature circulation. My daughter took [redacted] into hospital after a routine visit from the midwife as he was looking very dark and had lost 10% of his birth weight. At the hospital they took his oxygen sats and they were only 10%. They put him on a ventilator which then blew too hard resulting in a collapsed right lung. After what seemed like forever they guessed what the problem might be and gave [redacted] a drug to reverse the process of a duct in his heart closing up, so it would slowly start opening up again allowing some mixing of the blood. He was rushed down to Southampton General Hospital so they could perform emergency surgery to make another hole in [redacted] heart with a small balloon and it was during this emergency procedure that the collapsed lung was noticed and dealt with. [redacted] went on to have a successful arterial switch operation at a week old. After leaving Southampton hospital [redacted] had to be seen at Basingstoke hospital to have a

brain scan and development checks to ensure there was no permanent damage to his brain. He has been signed off from Basingstoke as his development was all within normal limits. [redacted] will continue to be monitored regularly at Southampton , all his life. Had the Pulse Oximetry test been available to [redacted] we could have prepared stright away for the switch operation instead of all that happened. [redacted] is the 5th child in my daughter's family, all from the same parents, 2 sisters and 2 brothers all of which are perfectly healthy so there was no reason to believe [redacted] wasn't going to be born perfectly healthy.

Best wishes
[redacted]

93.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

94.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

95.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

96.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My cousin died aged 20 because of a heart defects that could have been detected if he received the correct care. I feel strongly that all newborns should receive this screening.

Yours sincerely
[redacted]

97.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

98.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

So far, five members of my family have been diagnosed with Brugada Syndrome as adults, with many still to be tested.

Yours sincerely
[redacted]

99.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with a heart condition and has gone through alot. Im lucky they found her heart defect before she was born. Iv know others who was not lucky to found out till to late after birth.

Yours sincerely
[redacted]

100.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

101.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,

[redacted]

102.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

103.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

As a research associate who works in the area of cardiac physiology I understand the impact a congenital heart disease can be to not only the child but also the family. Therefore I cannot emphasise enough, how essential the screening of newborns for congenital defects. Early detection and the following repair of congenital heart defects increases both life expectancy and quality of life for those who suffer from congenital heart disease.

Yours sincerely

[redacted]

104.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

105.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

Best wishes,
[redacted]

106.

Dear Mr Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in newborn babies. Our son collapsed at home at 2 weeks old. we had been sleeping and were woken by a midwife wanting to do her last check. She ended up having to resusitate him. He ended up with very slight brain damage. If she hadn't come at that time. We wouldn't have him today he would have died in his sleep . His condition was made worse because no one was aware that he had congenital heart disease. when I'd had my 20wk scan I was told that his heart had formed correctly. We have since been told that his condition should have been picked up then. When He had surgery at 2.5 wks his chances were 40% of getting out of the operating theatre alive. He his now 14 yrs old. By the age of 6 he'd had 3 lots of open heart surgery plus other surgery. He will need further open heart surgery in the next few years.

Yours sincerely
[redacted]

107.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

my daughter was born with tetralogy of fallot she scored very low on tests at birth but was only diagnosed two days after birth

Yours sincerely
[redacted]

108.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My second daughter was born with a hole in her heart, which was only identified by chance through the vigilance of a doctor. We were lucky it was identified as if the problem had been left undetected it could have caused complications for our daughter and a lot of anxiety for us as parents. Introducing this simple screening can only be a good thing - it is non-invasive and economically makes sense.

Yours sincerely
[redacted]

109.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

110.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]
111.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

[redacted]

112.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

113.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I have had two heart transplants and suffer from Right Ventricular outflow tract obstruction, Anything that can improve the standard of life of those with congenital heart disease is worth it.

Yours sincerely
[redacted]

114.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was seriously ill at 3 weeks and had to have an emergency heart operation which could have been better planned and would not have been so ill had her defect been discovered before we left the hospital.

Yours sincerely
[redacted]

115.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

116.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

117.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I would like to at our story. How you may guessed it is something is closed to our hearts. I will start with before I got pregnant with [redacted](who was born with TGA and large IVS) I lost a baby, week before Christmas so you can imagine, how over the moon we were when we found out I was expecting again but at 20 week scan I was crying again as we got told something is wrong with the babies heart, my thoughts were no, I cannot loose this baby as well. Specialist did told be (us) we were really lucky it was picked up at the 20 weeks scan as normally parents found out much later, at birth or when baby at home. Scans were been done and I was running around between three hospitals. I gave birth on 7 November 2012 at Chelsea Hospital and our baby girl was taking to the Royal Brompton Hospital by a special team called CAT's

[redacted] had her surgery on 14/11/12 when she was 7 day's old. She underwent an arterial switch operation, at theatre surgeon notice aorto-pulmonary window, this was excised strayed away. After surgery there was some bleeding but this settled rapidly. [redacted] did developed a low cardiac output state and required inotropic support for 3 days post operatively.
Surgery was done by Surgeon [redacted] and Dr [redacted], who asked us if they can put [redacted] case in to the medical book.

At the hospital I stop feeling sorry for myself as I met other parents, who did not know something was wrong with their babies heart as 20 weeks scan did not show anything and some of the parents lost their babies because of it it is so important you recognice Pulse Oximetry screening at birth as a parent I would not know how I would coped and explained our 8 year old (who was asking for baby sister as a Christmas present and she did not wanted anything else) why baby sister is not coming home.

[redacted] is doing well, we need to go back every 6 months, she could be having another surgery but it is not yet.

Kind regards,

[redacted] (mother of [redacted]) [redacted]'s Mended Heart. xxxxxxxxxxxx [redacted]

118.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Due to be a Geat Grandfather tomorrow. The baby will be born to a mother with Marfan Syndrome. Her father died at the age of 41 and we did not know of the problem until he was in his 30s.

Yours sincerely
[redacted]

119.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My father in law died of complications after having had a great attack at a young age, his father suffered the same. My father has had a heart transplant after contacting a virus. Whilst these are not congenital, I understand the pain & suffering heart disease causes. Please screen babies.

Yours sincerely
[redacted]

120.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Our son was diagnosed at 8 days old, but this test would have got him help sooner. Also many children would benefit from earlier diagnosis

Yours sincerely
[redacted]

121.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

The safest way to treat a condition is at an early age in controlled conditions and not when it becomes symptomatic.

Please consider this simple, available method of screening to save lives,

Yours sincerely

[redacted]

122.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

As a now 19 year old congenital heart patient, this is a cause very close to my heart, (if you'll excuse the pun). When my mother was pregnant with me, we were very lucky that my condition was detected very early on in her pregnancy, so that appropriate measures could be taken to ensure that I could recieve the appropriate treatment once I was born. Thanks to the this early detection, I was also monitored throughout my childhood and adolescence to ensure my heart was in a stable condition.

However, I am aware that many are not so lucky, and are unaware of having any sort of condition until they are well into their teens, and it is often too late. I have heard numerous examples of teens leading apparently normal and healthy lives, until one day collapsing in the playground at school. Therefore, I am sure you will understand the importance of early detection.

Yours sincerely

[redacted]

123.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

124.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I am the mother of a sixteen year old with severe congenital heart disease who was diagnosed antenatally, so accessed specialist services from the day he was born,which saved his life. However, I

have known other children who have not been as lucky as him because their conditions were not detected for some time after birth, so I am keen to support this campaign which offers such a simple way to make a difference.

Yours sincerely
[redacted]

125.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I have a congenital heart defect and although I was not breathing when I was born no one thought that it may be due to this. My heart defect was not discovered until I was 5 years old and fell seriously ill, at this point I had extremely serious hypertension (my systolic blood pressure was over 200). I have since had 2 strokes due to my condition and strongly feel this may not have happened if I was tested as a newborn and had been treated then.

Yours sincerely
[redacted]

126.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I was born with a congenital heart defect which was not diagnosed until after birth. I nearly died because of the lack of testing and if it had not have been for a nurse spotting my symptoms I would not be here today. Sadly many newborns are not as lucky as I was. My condition would have been detected by pulse oximetry as would have many babies whose conditions were not picked up by a medical professional like mine was.

Yours sincerely
[redacted]

127.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

[redacted]

128.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

my mother and father found out in one of their maternity scans that I was going to have a collection of heart conditions, I am now 14 and still suffering with a collection of congenital heart defects and I'm am fitted with a pacemaker, i have had several operations and i think that it is necessary that parents are made aware of there child's condition so I feel that it necessary that all children are screened at birth

Yours sincerely [redacted]

129.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with a CHD and left hospital undiagnosed. This was thankfully picked up by our GP l at her 8 week check.

Yours sincerely
[redacted]

130.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I have a congenital heart defect which was not diagnosed at birth and therefore feel that all newborns should be screened.

leavinlg many babies undiagnosed for weeks, months or even years;

Yours sincerely
[redacted]

131.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I almost lost my son [redacted] due to a delayed diagnosis after his birth. This screening would have helped him receive trearment much sooner than he did, with less risks.

Yours sincerely
[redacted]

132.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

133.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

134.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with a complex cyanotic congenital heart defect. To date she has had four open heart surgeries and 4 cardiac catheters. She was left undiagnosed for 4 weeks when she went into heart failure. We were made aware that had this been picked up at birth she may not have needed as many surgeries. Pulse oximetry is a cost effective test than has been researched.
Yours sincerely
[redacted]

135.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

136.

Dear Mr Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening

My little girl was born with the most serious heart defect and it wasn't picked she could have died it needs sorting !!!

Yours sincerely

[redacted]

137.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

138.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

139.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

[redacted]

140.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Our daughter has ToF, which is usually diagnosed during pregnancy, however it wasn't, at any of the 4 scans we had.
She had a murmur that our doctor noticed at 5weeks when we went to get a cough checked, but this wasn't noticed at birth. She has now had surgery to repair it, but everyone we knew was shocked that it was missed at birth and while I was pregnant. We were very fortunate that [redacted] coped surprisingly well with her condition from birth, but I know of many others that weren't so fortunate, and if things as obvious as a heart murmur are missed during the newborn check, then how can we be certain that babies are being properly checked for heart conditions unless they have a specific test to check them. PLEASE make this a mandatory screening at birth! as so many parents never get to see their children grow up because they're little ones never made it past a few weeks or months due to lack of such a simple check at birth.

Yours sincerely
[redacted]

141.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with a complex CHD which was missed at the 20 week anomaly scan. We almost lost her at birth & spent a traumatic few days with her in PICU. I have met many other families doing the last year, some of whom have lost children or have children that have suffered brain damage as they cardiac arrested at home after their PDA closed. This would never have happened had they had a pulse ox at birth & thus checked for CHD

Yours sincerely
[redacted]

142.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My child suffered a cardiac arrest in my arms when he was 9 days old as he had an undiagnosed heart defect. He went on to have open heart surgery a few weeks later once he stabilised. He bled onto his brain as a result of being resuscitated for 17 minutes. A pulse oximetry test may have helped diagnose him before he became so ill.

Yours sincerely
[redacted]

143.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

144.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

On July 12th 2010, I gave birth to twin boys, I pointed out to the midwife that my son was blue and kept querying was this normal? My son's heart stopped one month later and we were blue lighted to the Royal Brompton Hospital were he was diagnosed with Complex Tretalogy of Fallot and underwent emergency surgery. We are very lucky to still have him, his SATS on admission were 25 - 40%, he was in acute heart failure. If he had had the pulse oximetry test when born, then his heart condition would of been picked up - surgery would not have been an emergency and maybe his start to life would of been a lot less traumatic.

Yours sincerely
[redacted]

145.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.
My Daughter was diagnosed within heart condition at the age of 7. I have been told by cardiologists that this would have been something that she was born with. I knew for years that there was something 'not right' when she was a baby, but nothing I could put my finger on, until her condition manifested itself at the age of 7.

Yours sincerely
[redacted]

[redacted]

146.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My Son Was Born With A Congenital Heart Disease which was not picked up until he was 6 weeks old after being admitted to hospital by ambulance as he was having respiratory distress. my son ended up on PICU needing to have life support and machines to help him breathe. It wasn't until his third week of admission that the doctors checked my sons heart after I requested it to be done. they found that he had a defect called a double aortic arch and he needed an immediate operation or he wouldn't survive or live without life support. his operation was a success but has left my son with respiratory, feeding, swallowing problems and behaviour problems due to a condition called trachea malacia which was caused by his heart defect. that cuts off the airway which results in brain damage. thankfully my son was lucky and not much damage has been done to the brain but not every child has been. my son has a long road ahead before he is fully healthy which could of been a lot different if his defect was picked up at birth or even on the ultra sound test. this defect has been proven to be picked up on ultra sounds but even though I had a total 0f nine scans not ones was this picked up.

Unfortunately it is estimated that around a third of children with congenital heart defects leave hospital without being diagnosed,

Yours sincerely
[redacted]

147.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son had a congenital Heart defect that was picked up a few weeks prior to the due date following my wife's involvement in a traffic incident. Had this not been picked up we could have left hospital without knowing our son had a serious condition which could have lead to serious consequences.

Yours sincerely
[redacted]

148.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

149.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My nephew had heart failure aged 9 days due to an undetected congenital heart defect. He died in my sisters arms. Luckily the incident happened in A&E - his parents instincts saved him. He was revived, but after 17 minutes wthout oxygen he suffered a bleed on his brain which left surgeons unable to perfom essential heart surgery until he was stabilised. His surgery was sucessful, but we have had to wait over two years to be reassured that there does not appear to be permanent brain damage. My nephew would have needed surgery regardless, however this test would have enabled maternity staff to pick up the defect and schedule the surgery quickly and with less trauma to my nephew and his parents.

Yours sincerely
[redacted]

150.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter, now in her forties, was not diagnosed with Patent ductus arteriosis (I think that is the correct condition) until she was in her teens. Fortunately, there was no need at that stage for medical intervention but it could have been very different. The loss of a child at any age is extremely distressing for parents but to lose a child when it could have been prevented by screening is heartbreaking.

Yours sincerely
[redacted]

151.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Having worked within a cardiology department, and being a mother myself, I feel that something that costs very little and takes minimal time, but that could save lives, should be implemented without question.

Yours sincerely
[redacted]

152.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with congential heart disease, I was lucky and I found out on my 16 week scan that my daughters heart wasnt growing properly and needed surgery within 5 days or she would have died. I met a family who was extremely lucky in Birmingham Children's Hospital that didn't know this about their child and was rushed from Dudley to Birmingham because after a few hours old wasnt breathing properly and was looking slightly blue. If a test is available in 5 hospitals then it should be available in all uk hospitals. if this test can save live why do we need to petition it should just be available as part as a general screening in newborns.

Yours sincerely
[redacted]

153.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted] was born with a rare heart disease that dis not get picked up until she was 4 weeks old. We found out we could have easily have lost her within that time and by some miracle we hadnt, But had this simple uninvasive test been carried out alongside the other newborn routine tests this would have been picked up on sooner and got her in the safey of neonatal special care Straight away where she needed to be ands referred to the freeman hospital where she would have recieved her first life saving surgery sooner than she did.

Yours sincerely
[redacted]

154.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted] was born [redacted] 2011 with Truncus arteriosus type 1 and was not diagnosed pre birth . [redacted] was lucky that the doctor checking her over heard a murmur, which the investigated further, which I've been told is not easily detected and common in newborns. [redacted] had open heart surgery at 4 weeks old and has gone on to have one other and 3 keyhole surgeries. If [redacted] hadn't had surgery she wouldn't have lived past 3 months.

Yours sincerely
[redacted]

155.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

A friend of my daughter had a congenital heart problem diagnosed in her second child during the pregnancy but I would definitely support Congenital Heart Disease screening in newborns. It should be added to other newborn screening which is already carried out.

Yours sincerely
[redacted]

156.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My eldest daughter was only diagnosed with a congenial heart defects at 2 years old after a routine appointment at the GPs. We suddenly went from thinking we had a healthy child into dealing with supporting her through open heart surgery. The testing would not have changed [redacted]'s diagnosis but it would have given us a chance to prepare for such major surgery.

Yours sincerely
[redacted]

157.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I nearly lost my son at three weeks old due to an undiagnosed heart condition that could have been picked up if this test had been performed. Thankfully my son record quickly from his surgery, but my mental healing took months of medication and therapy due to suffering from post traumatic stress disorder which was down to the emergency situation we found ourselves in

Yours sincerely
[redacted]

158.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I am a qualified paediatric nurse and worked for many years with children with congenital cardiac defects. I know how simple the pulse oximetry test is and that it only takes a few seconds to carry out. It is unobtrusive to the baby and would cost nothing to the Hospital. Yet it could be the difference between a baby being diagnosed and treated in hospital or getting dangerously sick at home without professionals on hand to help. This test really could be the difference of life and death to many babies born with CHD.

Yours sincerely
[redacted]

159.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My granddaughter, who is aged seven weeks, has just been discovered to have a hole in her heart. Had this screening been available to her as a newborn baby the diagnosis would have been made and treatment could have begun earlier. I feel that it is essential that screening at birth should be available to every child. From a cynical point of view the cost of such screening would be no doubt much less than the cost of treating a poorly child later on..

Yours sincerely
[redacted]

160.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

161.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

162.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

163.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My nephew was born with a heart defect which luckily was picked up the day he was born. He underwent open heart surgery at 5 days old. So I know how very important these tests are. My niece has also just been born she was small and very early and it was only because they were keeping an eye on her for different reasons that they realised at 3 weeks old she will require surgery too. That's 2 babies in my close family in the space of a year!! So these simple tests are vital.

Yours sincerely

[redacted]

164.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I personally suffer from an extremely rare heart condition which remained undetected until I was in my early twenties. I am fortunate that it did not cause me problems in childhood, however screening would most likely have highlighted a potential problem & risk.

Yours sincerely

[redacted]

165.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

166.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

167.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

168.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

No child should die needlessly if it is at all avoidable.

Yours sincerely
[redacted]

169.

Dear John Marshall,

Template text removed to reduce file size. See green text above.
Best wishes, [your name]

170.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My grandaughter was born with tetrology of fallot. Fortunately it was diagnosed at her 20 week anomoly scan. Due to the complexity of her defect she had to be born in Bristol close to the childrens cardiac unit incase she needed surgery when born. If she hadnt been diagnosed before birth and didnt have the opportunity of pulse oximetry test we would have taken home a very sick baby and the outcome may have been very different.
I know many babies die needlessly every year because their defects are not detected before birth. I also know the pulse oximetry test is not 100% at detecting a heart defect but it is better than nothing!

Yours sincerely
[redacted]

171.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]
172.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My beautiful niece has just been diagnosed with 2 holes in her heart, at 7weeks old. But 7 weeks of struggling with feeeds and constantly sleeping. A scan at birth would have seen these and her parents could have taken advice to improve things for her.

Yours sincerely

[redacted]

173.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

174.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

It's a "no brainer"!

Yours sincerely

[redacted]

175.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I have a congenital heart defect myself, called Tetralogy of Fallot. In the 1960s when I was born there were no such non-invasive tests that might have led to a diagnosis of my condition. In fact it was not diagnosed until I was 4 years old. I have had 2 open heart surgeries and live a pretty normal life, but my condition has put me in touch with many parents whose children were not so lucky and have sadly passed away, as they were too poorly to be treated in time.

Yours sincerely

[redacted]

176.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with 5 hear defects thankfully picked up in scan had it not she would have been sent home after birth and would have died at home that night.
We support families via our charity Lagan's Foundation. Alot of damilies were not caught at scan 74% and they found iut when their children went In to heart failure ir arrest situations. Horrible to think this quick and simple process could havw savwd them from that! .
Yours sincerely
[redacted]

177.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

178.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

179.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Every child should be screened at birth, to help save lives.
Yours sincerely
[redacted]

180.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son has a rare condition and was picked up before birth but there are hundreds of children condition that ain't picked up

Yours sincerely

[redacted]

181.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted] was born with Transposition of the Great Arteries that was diagnosed at birth. It was only the quick thinking of the paediatric doctor to undertake a saturation level test that saved her life when we were ready to be discharged. If This had been missed (my son Healthy Heart saturation level was never checked) we would have taken her home and we would have lost her - she was literally hours from death.

Yours sincerely

[redacted]

182.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born with a congenital heart defect that was diagnosed when my wife was pregnant. However, if this hadn't been picked up then, Harry would have been born blue with low sats. The screening would have identified his low oxygen saturations and therefore led to his diagnosis. It could potentially have saved his life.

Yours sincerely

[redacted]

183.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son has tetralogy of fallots! Luckily we found out durimgy 20 week scan, but if we hadnt had found out then something like this would have picked it up! I have met quite a few mummys who didnt find out their child had tetralogy till 3 or 6 months! Something like this would have given them extra time to get everything through their head before their child had open heart surgary!

Yours sincerely
[redacted]

184.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

185.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

186.

Dear Mr Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in new-borns.

I have a congenital Heart defect called Transposition of the Greater Arteries, and I was lucky that it was picked up in 1981, but I know a lot of babies defects are not picked up later. I now know how my parents felt all these years ago, as in 2003 I had a son who has diagnosed with pulmonary stenosis.

Yours sincerely
[redacted]
187.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My grandson died at 4 weeks old and was born with heart problems. Please agree to this screening to help save lives.

Yours sincerely
[redacted]

188.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

189.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Fortunately my sone as born complete healthy however I have had friends who have not been so lucky who have had children born with heart disease that has gone undetected.

Yours sincerely
[redacted]

190.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My cousins daughter was born with CHD and although bow thankfully a healthy 2 year old it has been a hard fight for her and the worry will always be there for her family.

Yours sincerely
[redacted]

191.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

192.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My little girl was born with a very complex heart condition. We were fortunate enough to find out at my 20wk scan but I knew a lot in the heart community that weren't so fortunate and was sent home with a poorly child. They didn't know anything was wrong until routine check at docs or even when there child goes lifeless and blue.

Yours sincerely
[redacted]

193.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

194.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I am [redacted] I'm 26 I have two beautiful children, I have a AVSD and mine wasn't diagnosed till I was 17 months after my mum continued to take me to the doctors but they wouldn't believe anything she said. They finally picked it up when I went for an operation on my thumbs and my mum asked the doctor to check my chest and they picked it up straight away! I had OHS when I was 2 and at 5. I still have two leaking valves but have regular check ups at at Thomas' hospital. So I do think it's very important to do early checks! Both my childrens hearts were checked by a fetal scan and they were both clear!
Yours sincerely
[redacted]

195.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

if pulmonary ox tests were in the uk oy would stopamy families going through what we went through. we took our son home as normal believing that everything was fine... until... day 9 when my little boy couldn't breathe we rushed him to a&e to have test after test done. they rhought he had an infection so treated with antibiotics iv. they did a lumber punch test, nasal swabs, sweat gland swabs and much more just to list a few.my little boy had 2 days of testing before a dr came on her normal ward round and thought she could hear a murmur.An ecg later and we discovered something wasnt quite right. then an ecco and found out my son has mitral valve stenosis amd regurgitation. Small asd. coarctation of the aorta. put this testing into the uk to stop more families going thrpugh the trauma we had to face!!!!

yours sincerely
[redacted]

196.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

197.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My baby girl is no longer with us following a heart transplant. She was born with a rare form of cardiomyopathy. More awareness needs to be raised and more money must be spent on research these killer diseases.

Yours sincerely
[redacted]

198.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

{My daughter went 6 weeks with an undiagnosed heart defect, which we were told at 6 weeks should have killed her,we were very lucky, as we found out completely by random chance, this should not be the case when it comes to babies lives, the NHS already have all the equipment needed to run the tests, so financial outlay will be minimal but the impact could be huge, for the families and babies whose lives it would save, I urge you to seriously consider this notion, especially as I continue to read and hear stories from other families who weren't as lucky as us and who have lost their babies life as a result of an undetected heart defect. Please have a heart and save a babies heart. As the Childrens Heart Unit Fund moto says "From kind hearts, grow healthy hearts."}

Yours sincerely
[redacted]

199.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born with a CHD and if it hadn't been for the consultant having a free hour when we went for a follow up for a heart murmur i may not of had my son here now. I feel extremely let find by my local hospital for failing to find this heart defect even after birth the midwives were so in helpful when he wouldn't feed
I'm a first time mum so to find out at 7 days old he had a large vsd

Yours sincerely
[redacted]

200.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

One of my very close friends lost her 6week old son last year due to a heart condition and I feel many people would benefit from this screening to help prevent this happening to more people..

Yours sincerely
[redacted]

201.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born 3days late and spent 3 days in hospital because he wasn't feeding properly it was discovered on his baby checks that's he had a heart murmur. The murmur faded but didn't go so we were asked to attend an appointment at 7days old and I the murmur remained a further appointment would be made for a scan of his heart lucky for us the neonatalogist had a spare hour so he scanned out son after his murmur was said to of still been there that was when his large VSD was discovered. Myself and my partner have never felt so let down by our local hospital for not detecting anything at both scans and after having him. To sit back and watch my fiancée heartbroken unable to look at our beautiful son without bursting into tears just ripped my heart out. The hole wasn't healing on its own so eventually at 11wks he underwent open heart surgery at Leeds general infirmary the whole ordeal still upsets us both now but we get to enjoy our little boy now who is now Almost 7 months old. These checks need to be compulsory it may not change the outcome at birth but it does give parents to be the chance to come to terms with it unlike us.

Yours sincerely

[redacted]

202.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

203.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely

[redacted]

204.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

205.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son [redacted] who is now 2 was diagnosed with Tetralogy of Fallot when he was 4 months old. His condition was completely missed during scans and after birth, even though he was born completely blue and 4 different nurses came and couldn't get the same heart rate when doing observations. The hospital let us go the same day. I took [redacted] to A&E when he was 4 months old with dehydration and was told about my sons suspected condition. If they had found it during my pregnancy I would have had more time to adjust to what our lives would have become.

Yours sincerely
[redacted]

206.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was not Pulse Oximetry tested at birth. She was later diagnosed at six weeks old with three major heart defects that the doctors say should have killed her. She was in critical condition but thankfully we found out before it was fatal. She had emergency surgery which saved her life. She was severely oxygen deprived for those first six weeks and may later prove to have brain damage due to this.If Pulse Oximetry testing had been implemented as a mandatory procedure, my daughter's condition would have been rectified before she was so oxygen deprived. This is such an important and simple procedure which is very cost effective. This test would save tiny lives and allow cardiac babies to have a better quality of life due to early diagnosis.

Yours sincerely
[redacted]

207.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]
208.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

[redacted]

209.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

210.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter was born with HLHS without being screen at guys hospital i would of never known untill after my child was born... [redacted] has had three open heart surgerys...not every hospital offers this screening amd i think every hospital should have this screening for C.H.D ...my daughter is going to be 15yrs old 15th december shes lucky to still be hrre we count how lucky stars everyday
.x

Yours sincerely
[redacted]

211.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

212.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Our family has had to cope with it's youngest member (a 4 month old baby) undergoing open heart surgery. Not something I would want any family to have to cope with.

Yours sincerely
[redacted]

213.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

214.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

215.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

216.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My older sister had a heart defect, they didn't find it till she was five and she has had multiple problems with it, she had open heart surgery and is now 19 and healthy but it's not the point, a young girl shouldn't have to go through such trauma, me at about 5 years old at the time of her operation had to go to a different school for a while and live with my nan, I'm 15 now and I still remember how much strain it out on us all, unfortunately my friends cousin died last night, he was just a baby, but he was scanned at birth and they were able to give him treatment which helped live as long as possible and let his parents come to terms with it, this is the way it should be.

Yours sincerely [redacted] (15)
[redacted]

217.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

218.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born with multi CHD's which went undetected till he was 12 weeks old and in severe heart failure. He had life saving surgery at 14 weeks. I believe screening at birth could've picked his illness up sooner.

Yours sincerely
[redacted]

219.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

220.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted] has a congenital heart defect which thankfully was picked up in the antenatal period enabling her to have life-saving surgery within hours of birth, but I know of several other parents whose child's heart defect was only picked up when they became seriously ill after birth and sadly some of these children died shortly afterwards. If they had had pulse oximetry screening after birth, the heart defects that these children suffered from could have been picked up more quickly and perhaps these deaths could have been prevented.

Best wishes,

[redacted]

221.

Dear John Marshall,

Template text removed to reduce file size. See green text above.

I have a child who was born with only half a heart and it was missed on all scans and at the check before we leave hospital. We found out he only had half a heart when we nearly lost him a week later and having his oxygen saturation levels before we left would of found it immediately as he only had oxygen of 70% It must be made compulsory for all babies to have a check before they leave the hospital. Studies have shown it works so please make it happen nationwide and we might be able to save more children Best wishes, Miss [redacted]

222.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

223.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.
I was born with a congenital heart defect & really think the screening should be a must.

Yours sincerely
[redacted]
224.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

225.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

226.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

227.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My daughter [redacted] was born with 4 heart defects. Not one was detected during pregnancy scans and neither was this test done at birth on her. [redacted] sadly passed away at just 9 months old because she wasnt saved soon enough.

Yours sincerely
[redacted]

228.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

229.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

The 2 day old son of a good friend of mine was diagnosed with a life threatening heart defect at 1 day of age prior to discharge from t the postnatal ward. Had he not had this test the probability is that sadly he would not have survived. We find out impossible to believe that such a simple, yet lie saving test that literally takes seconds is not routinely performed nationwide.

Yours sincerely
[redacted]

230.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Our daughter [redacted] was born with a severe and undiagnosed coarctation of the aorta. She passed her baby check and was allowed to go home from the hospital. Mercifully, we were readmitted because I was suffering from high and unstable blood pressure. We are very thankful that we were in hospital already on the day that [redacted] would have died because had she been at home it is likely we would have missed the subtle signs of heart failure until it may have been too late or until such time as parts of her body were damaged.

Yours sincerely

[redacted]

231.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son who is now 12 years of age was born with a heart defect and was lucky in that his was detected 24 hours after he was born. I feel that every newborn baby should be tested for heart defects at birth as the earlier it is detected the sooner it can be sorted out.

Yours sincerely
[redacted]

232.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

My son was born with coarctation of the aorta and required heart surgery at 8 weeks we was lucky as a heart murmur was detected and this was how it was found. This test should be made part of all newborn screenings it's painless and vital. It could potentially save a child's life.

Yours sincerely
[redacted]

233.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I work as an anaesthetist and think that early detection of heart disease is vital.

Yours sincerely
[redacted]

234.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

Yours sincerely
[redacted]

235.

Dear Mr Marshall,

Template text removed to reduce file size. See green text above.

I am a midwife and know that it takes only a few minutes to carry out pulse oximetry.

Yours sincerely
[redacted]

236.

Dear Mr Marshall,

I am writing in response to the UK National Screening Committee's consultation on their policy on Congenital Heart Disease screening in my daughter was born with tetralogy of fallots

Yours sincerely
[redacted]